DOCTOR OF EDUCATIONAL PSYCHOLOGY

Strategic asset or optional extra?
The impact of volunteers on hospice sustainability

Scott, Rosalind

Award date:
2013

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Professional Doctorate

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August 2013

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Acknowledgements

I would like to thank the Children's Hospice Association Scotland for supporting me with my Professional Doctorate and my colleagues for their patience, interest and encouragement as they shared in the highs and lows of my doctoral journey. I would also like to acknowledge the support of Help the Hospices who made a professional grant towards a proportion of my fees. I would also like to thank my supervisors Professor Divya Jindal-Snape and Dr Gaye Manwaring for all their support and guidance. I would also like to thank my friend and fellow student Lesley Greenaway for her support and insights, and lastly to my husband for his unending patience, tolerance and support.

Signed Declaration

I declare that I am the author of the thesis and unless otherwise stated all references cited by me in the thesis have been consulted. The work, of which this thesis is a record, has been done by entirely me and it has not been previously accepted for a higher degree.

Signed _____

Date _____

Abstract

Volunteering is a vital and integral part of UK independent hospices. Volunteers were the founders of many, if not all, UK hospices. Today, hospices are still heavily dependent on volunteers to raise funds and undertake a wide range of roles which help to support the patients and their families. Trustees, who are seen very differently to volunteers, also work in a voluntary capacity on hospice Boards. In this role they are responsible for the governance of hospices, carrying significant legal responsibility and setting the strategic direction. Yet volunteering is often overlooked at a strategic level and there are barriers to involvement in key areas, such as care. The purpose of this research was to explore the relationship between volunteering and the future sustainability of UK independent hospices. This was carried out by developing and testing a theoretical model of organisational sustainability in adult and children's hospices to explore how volunteering is understood by UK independent hospice senior staff, volunteers and trustees; to consider the influence of volunteers on four key organisational sustainability factors: governance; service delivery; hospice economy; and community engagement and explore whether there is a link between volunteering and hospice sustainability.. As this study had a strategic focus, the views of senior staff, trustees and volunteers were sought. Findings suggest that there is little understanding of the role of volunteers in governance, that there is a lack of planning for volunteer involvement and that volunteering has a strong influence on the sustainability of independent hospices. This is the first study of its kind and makes an original contribution to knowledge by producing evidence to demonstrate the relationship between hospice

sustainability and volunteering. It has the potential to influence and develop thinking about volunteering in UK independent hospices.

Introduction to the structure of the thesis

This thesis contains three components. These comprise an APEL Claim for 2.5 modules successfully examined (confirmation of which is included as APEL Appendix 7), a bridging paper which links the work covered by the APEL claim to the remainder of the thesis and a further 2.5 modules are submitted together as one piece of work incorporating both the literature review and research modules.

The APEL claim has five parts and is attached as Appendix 6. Part of the APEL contains previously published material in the form of book, a booklet and a journal article. To avoid copyright issues, these have been fully referenced in the relevant APEL section within an appendix to that section and are thus not included in the text of this thesis. These previously published documents have been submitted separately to the examiners along with bound copies of the thesis.

Bridging Paper

Introduction to the bridging paper

When embarking on my Professional Doctorate journey, I was motivated to make an APEL claim for 2.5 modules because of my previous experience of research, writing, presenting and publication. My aim was to review and critically evaluate my past work which had not previously been submitted for assessment for qualification of any kind. I also planned to use the opportunity to reflect on my research experience and identify strengths and areas for development in both my knowledge and practice.

My professional career has been spent in cancer and palliative care, with the largest proportion spent in the adult and children's hospice sectors. It was during this time that I developed a very significant interest in volunteering in hospices and palliative care in the UK and beyond. Hospice volunteering is a much under-researched field, however, in the last two years there have been a number of academic studies undertaken accompanied by a growing recognition of the importance of volunteering and the need for a more robust evidence base.

The aim of my practitioner research activities has always been to challenge and influence current attitudes, thinking and practice around hospice volunteering whilst also generating new knowledge in this field. I have a strong belief in the difference that volunteers make, not only to organisations, but more importantly

to the lives of whom they touch. It is this belief that motivates me to continue to research in this field and to learn more about the phenomenon that is volunteering in hospice and palliative care.

My APEL claim

During the work undertaken for my APEL, I reviewed and critically evaluated five previous areas of my work which covered both adult and children's hospices:

- research into issues of young adults with palliative care needs;
- development and publication of hospice toolkit for measuring volunteer value (adult and children's hospices);
- research study of the impact of volunteering in a children's hospice;
- my experience of editing a multi-author book on volunteering in palliative care (focused mainly on adult hospices with one chapter on children's hospices);
- my book chapter on volunteering in a children's hospice.

The process enabled me to identify the development of my skills and confidence in research. It was clear, however, that I needed to develop my skills in the following areas: critical analysis of literature, development of literature search skills and handling of information, design and structure of research projects and the critical evaluation of numerical data. Initially, I intended to do this by researching the transferability to the UK of the model of Neighbourhood Networks in palliative care in Kerala in India. However, as I

began to consider and distill my research ideas, I became more focused on exploring the link between volunteering and UK independent hospice sustainability. I was very aware of the historic importance of volunteering to UK hospices and of the significant time, skills and energy which volunteers continue to make. I understood the many roles which volunteers undertook but was also acutely aware that their contribution was often not considered at a strategic level. However, it was a discussion with my son about companies, strategic assets, how these might be defined, and their relevance to sustainability which prompted me to ask the question whether volunteering could be considered as a strategic asset and if so, how did hospices interpret and understand volunteering in this context. Keen not to lose sight of my interest in Kerala, I subsequently modified my plan so that I might explore the findings from my UK research study in the future in another country to explore their applicability.

New knowledge from APEL

I learned a great deal from reviewing work which I had previously undertaken. In looking at this afresh, I was able to identify areas for improvement in the following areas: research design and planning; undertaking a literature review prior to embarking on even small scale research studies; the need for improvement and consistency in referencing and also in writing and layout. I am now much more aware of the importance of the planning process prior to starting research, and the value of a clear, structured and achievable timeline. It was clear from reviewing some of my projects that a more critical analysis of literature would have strengthened these, particularly the projects discussed in

Parts 1, 3 and 5 of the claim. In reviewing my previous work for the APEL Claim, I was able to further develop my skills in critically analyising papers which helped me when undertaking my literature review.

I also valued the opportunity to review and observe the development of my skills in research and very much enjoyed reviewing my experience as a co-editor and the process of the editing project.

At the end of my APEL I recognised that there were areas of my work which required improvement as I moved on to the literature review and research modules of my doctoral studies. These included: literature search skills; critical analysis of literature; research design and timelines, gathering and analysis of quantitative data. I set out, therefore, to address these shortcomings in the following 2.5 Professional Doctorate modules.

Literature review and research modules

In approaching the literature and research modules, I decided to continue to focus on both adult and children's hospices. Whilst the structure and approach of both sectors is different, there are core elements of practice in volunteering in hospices which transcend settings. There are also a few organisations which provide both adult children's hospice services. I was also keen, therefore, to explore any similarities and differences between the sectors when considering their strategic perceptions of volunteering.

The literature review module helped me to develop effective, systematic literature search skills, through processes of applying theory to practice and by 'trial and error'. During the process I learned how to become more adept at interrogating databases and in developing effective and responsive systems for the handling of information. I taught myself to use Endnote, which on reflection was a mixed blessing and in the future I would opt to use my own electronic approach to the filing, retrieval and citing of literature. I am now much more disciplined in managing referencing and the literature review tested and improved my skills in the critical analysis of literature. I have found the application of this helpful, not only in the research context but also in many professional situations. Through this process I have also developed better attention to detail and I believe have significantly improved my referencing skills.

In developing the design and methods of my research study, I was able to build on previous research skills and knowledge. These, however, needed further development to meet doctoral standards and I also had gaps in experience of quantitative data gathering and analysis. In order to improve my skills, I was keen to use methods of data gathering and analysis which were new to me to enable me to improve my research ability. This I achieved through my decision to use an online survey which included both quantitative and qualitative questions. My previous research comprised mainly small-scale studies but my chosen sample for this research was the whole population of independent UK hospice organisations as listed in the Help the Hospices directory. This involved me in managing a much greater volume of quantitative and qualitative data than

I had ever done before and challenged my skills of analysis. Having now had experience of online surveys, I would be able to streamline my approach to analysis in the future and to use electronic tools such as spreadsheets more effectively. I have learned a great deal about framing questions to gather effective qualitative information and the importance of considering the construction of questionnaires to enable effective comparison across different groups of respondents. I have also learned the value of working to keep my research focus tight and achievable. My research study generated significant data and it became clear that it would be beyond the scope of this study to explore my finding with the model of Neighbourhood Networks in Palliative Care in Kerala, Southern India. This is something I intend to do once my Professional Doctorate has been achieved.

Original knowledge

I have certainly developed new knowledge and skills through the process of APEL, my literature review and research modules. I believe that my study has also generated original knowledge and new thinking about volunteering in independent UK hospices. My research is the first study to explore the link between volunteering and UK independent hospice sustainability. I have developed a Theoretical Model of Organisational Sustainability which has strong applicability to hospices in Scotland and England. I have subsequently developed the model based on findings from my study and have also identified risk factors to organisational sustainability. This model may also be used as a tool to explore hospice sustainability, particularly relating to volunteering.

Findings indicate that hospices depend greatly on volunteers for service delivery and sustainability. Indeed some have indicated that they would not be able to survive without the volunteering support that they have currently. Following this study I intend to test the applicability of my Theoretical Model in practice in non-hospice organisations and also with the Kerala programme to assess the broader applicability of the model. I also plan to further develop the model into a toolkit to enable hospices to consider their areas of strength and vulnerability in order to support the development of their strategic planning processes for volunteer involvement.

I hope that the findings from my study will challenge strategic thinking about volunteering in hospice and palliative care and will encourage a more structured and inclusive approach to the development of strategy. It is my aim to share my findings as widely as possible through delivery of papers at national and international conferences and by publication in peer reviewed journals.

Implications for my professional practice

An additional outcome from my Professional Doctorate has been the impact, not only on my research skills and ability, but also on my own organisation. A small part of my role as Director of Organisational Development in the Children's Hospice Association Scotland (CHAS) is the responsibility for the management of research. I have, therefore, tried to share my passion for and belief in practitioner research within CHAS. My aim is to develop research capacity within the organisation and to embed a culture of evidence-informed practice.

As my research knowledge, skills and confidence has increased throughout my Professional Doctorate journey, so has my contribution to this development at work. I have been involved in supporting staff to become involved in audit, evaluation and research, run workshops in developing abstracts for conferences, poster presentations and “Getting Started in Research”. I have established an Evaluation, Audit and Research group, the purpose of which is to support the development of such capacity within CHAS, monitor all activity to ensure a robust and consistent approach and record and report on all evaluation, audit and research activity within the organisation. I have also developed a CHAS Research Strategy and Policy. It is my vision that the group will develop further to include an academic and become an organisational ethics committee. It is rewarding to see the extent to which interest and confidence is growing amongst staff with increasing numbers of practitioners choosing to develop abstracts for submission to national and international conferences. This has resulted in a number of staff presenting their work nationally and internationally for the first time. As a result the research profile of CHAS is growing both within the UK and beyond.

Conclusion

My experience of the Professional Doctorate has been challenging, full of ‘highs’ and ‘lows’ and immensely rewarding. I have developed significant new knowledge, skills and confidence at the same time as an understanding of how much there is still for me to learn. This course of study has further deepened my belief in and passion for practitioner research and I am excited about the many

possible areas of future study that my research has identified. I hope to be able to follow up on some of these, and to work collaboratively with other researchers in so doing. There have been many wonderful opportunities which I have had as a result of this course of study, not least the chance to share my developing work at UK and international conferences and making links with researchers with similar interests in other countries. My Professional Doctorate has been a tremendous experience.

Chapter 1 A Review of the literature

1.1 Hospices and Volunteering: Setting the Scene

"You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die."
Dame Cicely Saunders (2006)

1.1.1 Introduction

Most of my professional career has been spent in cancer and palliative care settings and during that time I developed a deep interest in volunteering in both adult and children's hospice settings. Qualifying originally as a radiographer, I spent 10 years working as a Therapeutic Radiographer where I became particularly interested in the needs of those patients with little hope of cure and the care which hospices provided. A number of years later I had the opportunity to realise my passion to work in a hospice and took up post as a Voluntary Services Manager in an adult hospice, moving later to the same post in a children's hospice organisation. Whilst in this latter post, I was fortunate to have the scope to develop and structure a voluntary service from very small beginnings in a young and dynamic organisation. Through working alongside volunteers in both adult and children's hospice settings and networking with colleagues throughout the UK and beyond, I began to develop a growing understanding of, and curiosity about, the phenomenon that is hospice volunteering. This curiosity led me to learn more about the significance of practitioner research in contributing to the development of knowledge and practice. Having been enthused by seeing at first hand the difference that

research evidence can make to the improvement of practice, I have been motivated to continue to research in what is still a much under-researched field. It is my aim to challenge and influence current attitudes, thinking and practice around hospice volunteering in addition to adding to the body of knowledge in this field. I believe wholeheartedly in the difference that volunteers can make to any organisation and I have seen at first hand the impact that volunteering has as it touches and enriches the lives of many in hospices, and not only those of the patients and families.

Volunteers contribute significant time, skills and energy to UK hospices and yet their role and contribution is often overlooked. Hospices have a long and proud history of the involvement of volunteers. Doyle (2002) recognised that Dame Cicely Saunders, internationally known as the founder of the modern hospice movement, was a volunteer in the early and latter parts of her career. Indeed many hospices owe their very existence to founding volunteers and this will be explored further in 1.4. Despite the many changes and developments in both society and hospices since their inception, Scott, Howlett and Doyle (2009) assert that volunteers are still vital to the delivery of the care and support provided to hospice patients today. Volunteers undertake many roles within hospices. Some examples of these include proving transport to patients; supporting catering, gardening and housekeeping services; practical activities with patients; complementary therapies; befriending; counselling and bereavement care; fundraising and educating the public about the work of hospices. This section will set the scene by outlining the background to the literature review, setting hospices in the context of palliative care, define adult

and children's palliative care, give current facts and figures for UK hospices and explain the literature review methods.

1.1.2 Definitions

The purpose of this research is to explore the relationship between volunteering and the future sustainability of UK independent hospices. It is important at the outset to define the terms hospice, palliative care and volunteering in addition to understanding where hospices fit in to the spectrum of care described as 'palliative'. The concept of strategy and sustainability are also considered. The type of care delivered by hospices is palliative care. This care may also be delivered in other settings including hospitals, community hospitals, care homes and the community.

Hospices, however, generally deliver specialist care to patients with the most challenging and complex of palliative care needs. This care is holistic, providing both symptom management, social care, support to the patient's family, spiritual care and bereavement support. Often considered to be places where people go to die, the real focus of hospices is to increase quality of life for the patient, whatever period of time the person has left.

Definitions of palliative care for adults and children

The word 'palliative' comes from the Latin verb 'palliare' to cloak and could be considered to be the masking or alleviation of symptoms. The World Health

Organisation (WHO) (1998) has very clear definitions of both adult and children's palliative care, recognising the clear differences between the two groups. Defining adult palliative care, the WHO definition encompasses the importance of ensuring a good quality of life for patients and families through the prevention and alleviation of distress. This definition also emphasises the necessity for early diagnosis and treatment of all the components of pain, including physical, spiritual, psychological and social aspects.

In addition to these areas, the WHO definition for children's palliative care (1998) states that this care should begin at the point of diagnosis and should continue irrespective of whether the child is receiving active treatment for their illness.

Definition of volunteering

In the UK there is no legal definition of volunteering, however there are a number of definitions, which are all broadly similar. The Scottish Executive Volunteering Strategy (2004) gives a helpful statement, which outlines the main characteristics of volunteering as the giving of time without financial incentive or benefit to those beyond the volunteer's family. This not only helps the volunteer him or herself, but also other people, whether individual or groups, the environment or society as a whole. This definition also emphasises the importance of freedom of choice on the part of the volunteer.

Volunteering is a complex phenomenon and describes a spectrum of activity

from informal to formal. Rochester, Ellis Paine, Howlett and Zimmeck (2010) describe three main spheres of volunteering: activism where people campaign for a cause which they espouse; unpaid work or service frequently as part of an organisation; or serious leisure which involves the pursuit of a hobby as a volunteer. Rochester et al. (2010) describe informal volunteering as giving unpaid help to others who are not related to the individual whereas formal volunteering is giving this voluntary help through groups or organisations which benefit people or the environment. Formal volunteering, in contrast to informal volunteering is usually organised and often very structured.

Definition of sustainability and sustainable development

There are several definitions of sustainability, many of which refer to finance or the environment. However, Sustainable Measures (n.d.) consider that all definitions relate to working or living within boundaries, understanding the landscape and the links with the economy, society and the environment, and ensuring that both assets and opportunities are fairly and reasonably allocated. Brundtland (1987) considers that sustainable development is “development that meets the needs of the present without compromising the ability of future generations to meet their own needs” (p8). Miller, McCartney, Baron, McGurk and Robinson (2011) consider a number of areas that are key to the sustainable performance of organisations. These include integration of the goals of internal and external stakeholders with the purpose of the organisation; leadership with a clear vision of the future which empowers staff; appraisal and review of progress and impact; considering both the short and longer term; flexiblility and

ability to respond to change; and building capacity both in individuals and organisations.

Hospice sustainability might, therefore, be described as working within the limits of resources available with a clear understanding and effective response to the changing external influences of the economy, society, and the hospice and palliative care environment to ensure that all assets and opportunities are equitably maximised to provide equity of access to services for those people who need them both now and in the future.

Definition of strategy

The word strategy can be interpreted in many ways and leading authorities give a range of different definitions. The Chartered Quality Institute (n.d.) define strategy as a map for outlining the direction the organisation must take to achieve its values, vision and mission. Mintzberg (1998) considers strategy to describe the development of future plans which is also informed by patterns of organisational behavior that have developed over the years. Johnson, Scholes and Whittington (2012) describe strategy as “the long term direction of an organisation” (p3). The National Council for Voluntary Organisations (n.d.) not only supports the view of The Chartered Quality Institute, and Johnson et al. (2012) but also identifies the requirement for strategy to interact with the wider environment, and respond to and manage change. Taking into account the role of strategy within the field of hospice care, for the purposes of this study, strategy is defined as the set of goals outlining the long-term direction of the

organisation and the actions required to achieve these.

1.1.3 UK Hospices: definition, facts and figures

Independent hospices are charities dependent on funding from both statutory and voluntary sources. There are also a small number of NHS hospices. The hospice movement is well established within the UK with both adult and children's hospices providing care to these two very distinct groups. Help The Hospices (2010), an umbrella organisation set up to promote and support hospice care, describes hospices as a philosophy and approach to caring for people. Their definition encompasses the World Health Organisation (WHO) (1998) definition and emphasises the importance of helping those whose condition may be life-limiting to live as active a life as possible for the time they have left. Hospice care also extends to family and friends, and continues into bereavement. For the purposes of this research, therefore, the definition of hospice volunteering is: the time freely given by individuals, with no expectation of financial gain, to support hospice patients, their families or those who care for them and local communities with the intention of improving the quality of life, of adults and children with life-limiting conditions.

In hospices there are two types of volunteers: volunteers known as trustees who serve on the Board of the hospice and have responsibility for the governance and strategic direction of the organisation. There are also 'hands on' volunteers who help the organisation in a wide range of roles as previously discussed in 1.1.1. In the hospice movement, there is a clear distinction

between these two types of volunteering and it is clearly understood that when referring to ‘trustees’ that these are Board members and that ‘volunteers’ have a more operational role. This terminology will therefore be used throughout this research.

There are a significant number of hospice services throughout UK. Help the Hospices (2012a) give the following statistics for adult hospice services:

- 223 hospice and palliative care inpatient units;
- 291 home care services;
- 129 Hospice at Home services;
- 275 day care centres.

There are also 44 children’s hospice services with a total of 334 beds. A study undertaken by Devaney, Bradley and Together for Short Lives (2012) estimated that 7,638 children with life limiting conditions were cared for by children’s hospices in 2011/2012.

Within the 190 independent hospices that are members of Help the Hospices (2011), there are 14,000 paid staff. According to a study undertaken by Help the Hospices (2006a) the number of volunteers was estimated to be over 100,000 with an estimated value of £112 million per year. There is some debate about whether and how donated time should be quantified. The method used in this particular calculation is one method of conveying the importance and value of time and skills given by volunteers.

1.1.4 Context of the literature review

In the introduction, reference was made to the importance of volunteers to hospice services. Hospices and volunteering within the UK are both undergoing significant change. Some of this change is influenced by government policy, some by the changing impact of an ageing society living longer with a range of co-morbid conditions, and some by the changing expectations of funders and volunteers.

There is a paucity of research around the strategic impact and significance of volunteering in UK hospices, with much of the research focusing on volunteer motivations and management. It is also hard to assess how much influence any research findings have had on the development of volunteering models and practice in UK hospices, as experience suggests organic and localised growth. Hospice volunteering, however, does not operate in a vacuum and the wider landscape and theory of volunteering is helpful to the context of this literature review. Volunteering in the wider world is undergoing significant change with an ever-developing UK government focus on volunteering, changing demographics and volunteer expectations.

Palliative care is also a priority for governments across the UK, with the emphasis on the provision of palliative care for all regardless of diagnosis. This is set against a backdrop of an ageing population where the incidence of cancer and other life-limiting conditions is likely to rise. In the context of children's hospices, a recent study by Fraser, Miller, Aldridge, McKinney, and Parslow

(2011) suggests that the prevalence of children with life-limiting conditions is increasing across all four countries of the UK. Advances in paediatric medicine already affect the children's hospice population, where babies born very prematurely are now surviving, many with very complex and life-limiting conditions. Children who, ten years ago, would not have been expected to live beyond childhood are now living longer into early adulthood.

Calanzani, Higginson and Gomes (2013) suggest that these changing demographics will make increasing demands on hospice services and that hospices must consider how to increase or reconfigure services to meet these needs. Set within a context of predicted staffing shortages and actual funding shortfalls, hospices therefore face a changing and challenging future where they need to provide more care with fewer resources. This could result in a greater role for volunteers. Anecdotal evidence suggests that hospices are already considering volunteers in new more care -focused roles, borne out of financial necessity. I would suggest, however, that it is vital for hospices to approach such development in a planned and coherent way, identifying what skills are needed to achieve planned objectives and to consider where volunteers fit within the overall structure of the organisation. There needs to be an understanding of the strategic significance of volunteers and the role which they will play, both currently and in the future, in order to support the organisation to achieve its goals. It is also important to understand the influence of volunteering on future hospice sustainability. With a dearth of understanding and research in this area, this, therefore, is the focus of this literature review.

1.2 Literature Review Methodology

This section will describe the purpose, planning and approach to the literature review and the methods used for analysis. There is also a reflection on the challenges of the literature search and the range and types of documents available for the key areas reviewed.

1.2.1 Purpose of the literature review

The purpose of the literature review is to:

- Explore current palliative care policy and the implications for hospice volunteering
- Consider the role of volunteers in the development of hospices
- Explore the current trends in volunteering in UK and their impact on hospices
- Conceptualize the relationship between volunteering and future sustainability of UK independent hospices

1.2.2 Collection of data

Planning the literature search

I approached the literature search by following guidance in Hart (2006) on planning, in which he advocates six steps. These include: identifying the specific area; outlining the range of the project; considering the likely results;

consider the administration of the literature search –how findings are managed and collated; identify the sources for the search and lastly, undertake the search.

Having considered, reviewed and refined the topic through an iterative process, I initially explored the work of key authors known to me and began to consider the main areas upon which to focus the literature search. I then considered the time period which might be most relevant to the search, and how early in terms of dates I might need to go. I also began to define key words and phrases to use. The key words and phrases used in the search were: hospice models, hospice development, hospice management, hospice structures, hospice organisation, volunteering and hospices, volunteer value, palliative care policy, volunteering policy and volunteering trends.

Throughout all stages it was important to ensure that I did not stray from the focus of the literature review and I did this by regularly checking back to the purpose. In designing the system for recording data from the search, I decided to use an Endnote database to store all information. Alongside this I kept a note of the databases searched and the key words used. I also used a paper based filing system for printed documents, which were filed under the key the headings of: hospice development; government policy in palliative care, government policy on volunteering; volunteering in health; and hospice volunteering. Using Cross-Search, I began to identify the most relevant databases to search for my topic and began the literature search.

Sources used

A number of databases were searched: CINHAL (EBSCO), British Nursing Index, Intute: Health and Life Sciences, ERIC, SCOPUS, ASSIA (CSA) Cochrane Library and Google Scholar. Data was also sourced from UK Governments' websites and from organisations such as Help the Hospices, Children's Hospices UK (now Together for Short Lives), Scottish Partnership for Palliative Care, Volunteer Development Scotland, Volunteering England and the Institute for Volunteering Research. From significant practitioner experience of the field and previous study, I was aware of key authors and papers and sought these specifically, where I did not already have copies, and where these did not appear in electronic searches.

Criteria for inclusion and exclusion

The search was limited initially to published and unpublished papers written in English from 2000 to 2011 in order to keep the focus on current thinking. Scanning references from a small sample of documents, it was clear that many of the key articles relating to hospice history and development predated 2000. Therefore, literature of relevance to hospice history and development and hospice volunteering prior to this date was also included. There is no available research relating to the initial development of hospices. The reason for this may be that hospices evolved organically in response to perceived need rather than empirical research, and most hospice research stemmed from the hospices themselves once they had become established. The focus of such research was mainly to provide evidence for the wider application of their work.

The review of literature also identified a gap in research into volunteering in children's hospices. Papers were also identified for inclusion from citations in articles found during the search. I identified 89 papers for inclusion, of which only 28 were research based. Others were discursive papers, books, government documents and policy. A table of these papers categorised by type can be seen in Appendix 1. Criteria for inclusion and exclusion are outlined in Tables 1.1 and 1.2.

Table 1.1: Inclusion Criteria

Inclusion Criteria	Reasons
Literature written in English	Difficulties with translation and ensuring accuracy in translation. Lack of time and resources for translation to be undertaken.
Dates between 2000 -2011 with some key papers before 2000	I was keen to ensure the most up to date current practice and theory was included, unless a historical perspective was required. However there are some also key pieces of literature written before this date which were helpful to the topic and these were included. Another consideration, was the ability to manage the volume of papers found.
Published and unpublished papers	I did not want to assume that all information relevant to the topic had been published and knew of a number of valuable papers which, as yet, were unpublished. These I sourced from the authors.
Research studies including theses	To identify as much current relevant research as possible, both published and unpublished.
Policy and Government documents on palliative care and volunteering	This was a key source of information relevant to the context in which hospices and volunteers operate. It gave insight into government focus and direction relating to palliative care, hospices and volunteering.
Books	There is a lack of research literature in the field of hospice development and the role of volunteers in this area. Books were likely to be a useful source of discursive literature relevant to my topic.
Practice literature	There is a lack of research literature in the field of hospice development and the role of volunteers in this area and hospice sustainability. Practice literature was likely to be a useful source of discursive literature relevant to my topic.

Independent hospices	Independent hospices are only partially funded by the government and as such could be considered to be at more risk when it comes to sustainability than NHS hospices. Independent hospices generally involve volunteers in more diverse roles than NHS hospices.
Adult and children's hospices	I felt that the literature review would be of more value if it included both sectors.
Formal volunteering	The spectrum of informal volunteering is vast and often difficult to define. UK Hospices all involve formal volunteering approaches where volunteers work within a structure and are managed and trained, usually by staff.
Websites for umbrella organisations e.g. Help the Hospices, Together for Short Lives (formerly Children's Hospices UK)	These organisations are a valuable resource with regular updates of sector-specific information.

Table 1.2: Exclusion Criteria

Exclusion Criteria	Reasons
Literature written in languages other than English	Difficulties with translation and ensuring accuracy in translation. Lack of time and resources for translation to be undertaken.
NHS Hospices	NHS Hospices are ultimately fully funded by the NHS and I considered them to have fewer issues related to economic sustainability. Volunteers, whilst still widely used in this part of the sector, are more restricted in their activities because of trade union influence. Any relevant information identified which related to NHS hospices will be included.
Volunteers involved in health trials and research	This area is not relevant to the topic.
Informal volunteering	The spectrum of informal volunteering is vast and often difficult to define. UK Hospices all involve formal volunteering approaches where volunteers work within a structure and are managed and trained, usually by staff.
Volunteer management guidance e.g. recruitment, selection, training, support	This area is unlikely to be relevant to the topic, however any information which is relevant will be included.

1.2.3 Analysis of Data

Stage 1

Papers were initially screened for relevance by reading abstracts and conclusions. In developing a process for analysing the literature, I adapted Wallace and Wray's (2006) five critical synopsis questions: what is my purpose

in reading this; what are the writer's aims; what is pertinent to what I need to know; am I persuaded by the authors; and of what value is this to my study? Papers were read and summarised using a table format using the following headings:

- title, Author, Year;
- country;
- paper type;
- research methods;
- findings and discussion;
- my critique;
- relevance/use.

Stage 2

In order to meet the aims of the literature review, the search focused on seven key areas: the history of hospice development; volunteers and their role in hospice organisational development; UK palliative care policy; UK volunteering policy; volunteering in health; volunteering in hospices; and hospice organisational influence on volunteering. Notes were reviewed and common themes identified and collated within the seven broad headings outlined above and critically analysed. Notes were made linking ideas, authors and views. This stage also led to further papers being identified, obtained and analysed as outlined above.

The types of literature available across the areas of focus for the review varied greatly. With the lack of research into hospice development and volunteering

within that context, I drew heavily on narrative accounts, oral history, historical accounts and biographies. As there was so little literature relating to hospice models and structure, I concluded that hospices had evolved and grown organically, based on the passion, belief and experiences of individuals rather than from a research evidence base. Anecdotal evidence suggests that hospice structures vary although core elements may be similar and this might support the lack of research evidence in this area.

Searching for policy in palliative care and volunteering elicited a raft of documents, not all of which were relevant to the topic. Volunteering in health and hospices produced a significant body of evidence, much of which related to volunteer motivation and management. The literature search identified gaps in research regarding hospice models and organisational structure. There is also a dearth of research into the contribution which volunteers make to end of life care and their impact on the sustainability of hospices in the UK.

1. 3: The Policy Context

"A policy is a temporary creed liable to be changed, but while it holds good it has got to be pursued with apostolic zeal." (1922). Mohandas Gandhi

1.3.1 Palliative care policy implications for hospices and volunteers

Volunteering in any organisation is influenced by many factors, including those external to the organisation, at local, national and even international levels. Given that the literature supports the idea that hospices are dependent on volunteers to deliver their current levels of service, (Davis Smith (2004), Help the Hospices (2006a) Scott Howlett and Doyle (2009), Sallnow (2010)), the first part of this section will explore how well current palliative care policy recognises this. Consideration will also be given to the resulting implications for hospices and hospice volunteering. The second part of this section will move on to consider literature on the volunteering policy context, changes in social trends and volunteer expectations in the UK and also explore their potential impact on hospices.

Palliative care has previously never been such a prominent part of UK governments' thinking as in recent years. During this time, a number of significant government and policy documents have been published: Better Care, Better Lives (2008); Living and Dying Well (2008) and A Framework for the Delivery of Palliative Care for Children and Young People in Scotland (2013) from the Scottish Government; End of Life Care Strategy from the Department of Health in England (2008), the Palliative Care Planning Group Report to the Minister of Health for Wales (Sugar, 2008) Together for Health –

Delivering End of Life Care (2013) from the Welsh Government and the Palliative and End of Life Care Strategy for Northern Ireland, (2009). This has presented tremendous opportunities for hospices in raising the profile of their work at government level. It has also presented a platform from which hospices have been able to influence the debate, discussion and direction of palliative care development within the UK.

These policy developments have taken place against a healthcare landscape where there are increasing expectations of the NHS to fund and provide care at the very forefront of medical science. This is also set within the context of a growing elderly population with increased life expectancy with resultant rise in cancer and other life-limiting conditions. In addition children's hospices are seeing a changing population ranging from newly born babies, to young adults in their 20's and 30's who have lived longer than expected, many of whom have increasingly complex care needs. The consequences for both children's and adult hospices is likely to be a greater demand for their services set against significant funding cuts facing the statutory and voluntary sectors and a predicted shortage of healthcare staff.

Health is a devolved matter; therefore, governments in Scotland, England, Wales and Northern Ireland develop policy locally. There are, however, common themes running throughout national policies. One of the main differences is the policy approach to palliative care for children and young people. This has been considered separately from the adult sector initially only in England in 2008 but also more recently in Scotland in 2013 and could be

construed, therefore, as having a higher priority there than in the other two nations. A brief summary of the most recent key policies on palliative care for each UK country, with specific relevance to hospices, is outlined in Tables 1.3, 1.4, 1.5 and 1.6 on the pages which follow.

Table 1.3: Key Palliative Care Government Documents and Policies in Scotland

Palliative Care Government Documents and Policy in Scotland		
Year	**Policy Title**	**Key Points**
2006	Joined up thinking. Joined up care. Scottish Partnership for Palliative Care (2006)	Recognition of the need to extend palliative care beyond cancer to other serious non-malignant conditions. **Role of volunteers noted.**
2007	Palliative and End of Life Care in Scotland: The Case for a Cohesive Approach Scottish Partnership for Palliative Care (2007)	The inequality of services needs to be addressed by extending palliative care to all conditions. There is also a key role for generalist care providers in the delivery of care. **Volunteers not mentioned.**
2008	Review of Palliative Care Services in Scotland. Audit Scotland (2008)	A report by Audit Scotland. Identified the need for better co-ordination of and a planned approach to care. Almost 50% of funding spent on specialist palliative care comes from voluntary sector therefore there are implications for the sustainability of services. A significant percentage of specialist palliative care delivered by independent hospices. Recommendations include: need for palliative care action plan to ensure consistency and sustainability of services; needs assessment for all people with life-limiting conditions including non-cancer; improving access to palliative care; effective commissioning and monitoring to ensure cost effectiveness; development of consistent referral criteria for referral to specialist palliative care services. Need for consistent approach to funding voluntary hospices. **Volunteers not mentioned.**

2008	Living and Dying Well – a national action plan for end of life care in Scotland. Scottish Government (2008)	An action plan to ensure equality of access to quality palliative care regardless of medical condition. Recommendations include; effective palliative and end of life care needs assessments for patients and carers; effective planning and delivery of care; effective communication with patients and families and co-ordination of care; skills training for professionals; key role for hospice practitioners in sharing expertise. Identification of seven work strands for development of recommendations on implementation: standards for palliative and end of life care; national guidelines and referral criteria for palliative and end of life care; assessment tools and advance care planning; information for patient and carers on palliative care and end of life; services for life-threatened adolescents and young adults; addressing palliative care from public health and health promotion view. **Volunteers not mentioned.**
2013	A Framework for the Delivery of Palliative Care for Children and Young People in Scotland Scottish Children and Young People's Palliative Care Executive Group (SCYPPEx) (2013)	A framework to ensure joined up care and pathways for children and young people with a life-limiting condition. There should be recognised pathways across all Health Board areas and also within each area. The framework applies to Health Boards and partnerships with Social Work, Education, Children's Hospice Association Scotland and other voluntary organisations to ensure a model for palliative care which is integrated across all services. The model must give consideration to the needs of the child and young person in relation to age, geography and social needs. Lead professionals are required in each Health Board, services planned in response to prevalence, equity of access to palliative care which is appropriate to individual needs, flexible, and encompassing medical, emotional and spiritual needs. Choice of place of care and place of death. To be delivered timeously by a competent and skilled workforce. **Volunteers not mentioned.**

Table 1. 4: Summary of Key Palliative Care Government Documents and Policies in England

Palliative Care Government Documents and Policy in England		
Year	**Policy Title**	**Key Points**
2007	Craft, A. and Killen, S., (2007) Palliative Care Services for Children and Young People in England.	Report on a wide review of children's palliative care in England. Recommendations include a national strategy for children's palliative care; joint working to ensure effective planning and delivery of services; voluntary sector equal partners in planning and delivery; development of effective data collection processes; improving access to care; end of life care for children given the same priority as that for adults; improving the transition process for children moving into adult services; improved commissioning and sustainability; development of training for professionals. **Volunteers not mentioned.**
2008	Better Care, Better Lives Department of Health (2008)	Outline for improved palliative care services for life limited children and young adults. Recommendations included: better data collection systems; improved needs assessments and support; improving equality of access; improved partnership working; care to be delivered in the best place for child/young person and family. **Volunteers not mentioned.**
2008	End of Life Care. National Audit Office (2008)	A review of end of life care provision by the National Audit Office. Findings included: lack of equity of access; people not being able to die in place of choice; a need to develop skills of professionals; need for a cohesive approach to delivery and commissioning of services. Recommendations included: extending palliative care to all regardless of diagnosis; better use and redistribution of Primary Care Trust resources; hospice skills used more widely for non-cancer through outreach services and training for other professionals. Recognition was made of the significant proportion of specialist palliative care delivered by independent hospices. **Volunteers not mentioned.**

2008	End of Life Care Strategy Department of Health (2008)	Focus of the strategy is raising awareness of and changing attitudes to end of life care through engagement with communities; effective commissioning of services; improving professional skills to aid the 'diagnosis' of approaching end of life; effective care planning and co-ordination of care; improving access to care; training for professionals in end of life care; support for carers. Hospices recognised as centres of excellence. Recognised financial implications of developing specialist palliative care outreach to non-cancer patients and to settings beyond hospices. **Volunteers not mentioned.**

Table 1.5: Summary of Key Palliative Care Government Documents and Policies in Wales

Palliative Care Government Documents and Policy in Wales		
Year	Policy Title	Key Points
2008	Sugar, V. (2008) Palliative Care Planning Group Wales: Report to the Minister for Health and Social Services.	Found gaps in the provision of services; lack of accessibility to services because of lack of staff and geographical problems, (including transport), variability in commissioning services. Recommended development of 24 hour service to all patients; development of regulatory body to monitor standards; improved training and education for specialist and general professionals. **Volunteers recognised as vital to providing transport to patients where public transport is poor.**
2013	Together for Health - Delivering End of Life Care - A delivery plan up to 2016 for NHS Wales and its partners. (2013)	Framework for local Health Boards, NHS Trusts and voluntary sector partners. Reducing inequalities, improving access to end of life care for people regardless of diagnosis. Aiming to achieve more openness to and planning for death. People who are dying to have access to high quality care regardless of location or diagnosis. Choice of place of death. The framework gives clear expectations of the NHS in Wales and also of organisations with whom it works in partnership, particularly hospices and social care organisations. **Volunteers not mentioned.**

Table 1.6: Summary of Key Palliative Care Government Documents and Policies in Northern Ireland

Palliative Care Government Documents and Policy in Northern Ireland		
Year	Policy Title	Key Points
2009	Palliative and End of Life Care Strategy for Northern Ireland. Department of Health Social Services and Public Safety (2009)	Focusing on the needs of the person rather than the illness and part of care delivered to patients with progressive terminal conditions. Understanding what palliative and end of life care is; effective care provided by skilled staff; effective communication and choice, effective co-ordination and continuity of care and support. **Volunteers identified as part of the specialist palliative care team and a vital element as increasing levels of care are provided in the community.**

In considering the focus of this literature review on hospice volunteering, it initially appears that these policies do not recognise the role of volunteering in this field. Volunteering has been ignored in both Scottish and English policy. The focus of the majority of the policies is the development of palliative and end of life care within the NHS, care homes and the voluntary sector. Given the role of volunteers in the NHS and voluntary sector, their omission is significant. As with all policies there are often unintended consequences for other spheres of practice and these policies will undoubtedly influence the work of independent hospices and volunteering therein.

An extensive project was led by the Scottish Partnership for Palliative Care (2006) with the aim of widening access to care for patients with life-limiting conditions other than cancer. The project gathered evidence from literature and consultation with a wide range of professionals, carers, statutory and voluntary organisations during a two-year period. The numbers of those involved in consultation is not explicit and it is not clear whether volunteers were included in the process. One of the main conclusions from this project was that palliative

care should be equally available to everyone on the basis of need rather than diagnosis and not focused solely on those patients with cancer. The findings identified a need for care to be provided locally, through services and professionals working together, and the development of closer links between health and social services. The project also identified the need for hospices to focus their skills and resources, and revise their referral criteria, to include patients with non-malignant conditions. In this report there is also recognition of the significant role, which volunteers have to play in supporting those with non-cancer diagnoses. The range of support which volunteers provide to patients, and the importance of their role in the hospice setting is also recognised.

Many of the findings of this report are echoed in the palliative care policies of today. It is concerning that this volunteering strand was lost in subsequent Scottish policy, especially with the NHS focus on volunteering which was developing at the same time. In Better Health Better Care, (2007) the Scottish Government action plan to improve health and patient involvement in Scotland, the commitment to volunteering was clearly stated. Not only did it contain plans to review their strategy on volunteering in the NHS and to recognise voluntary sector contributions, it also stated that all NHS Boards would achieve the national standard for volunteering: Investing in Volunteers by March 2011. This would suggest, therefore, that the role of volunteers was considered to be an important part in meeting the aims of Better Health Better Care.

The focus of many of the ensuing policies set a range of expectations of hospices. Not only are they expected to extend their care to those patients

with non-malignant conditions, but also to play a key training role in cascading the significant experience in the care of patients with complex needs to generalist staff within the NHS and care homes. It has to be recognised, however, that the majority of hospices have long provided education, training, support and advice to many staff in statutory, private and voluntary care settings. When formalised within a policy context, however, the question has to be asked as to how easily hospices, as charitable organisations, will be able to support and fund such potentially significant developments in their services. If new types of patients are to be cared for, and additional services required, this will most certainly have an impact on the work of volunteers within these settings in both care and fundraising. It is regrettable that this has not been considered in policy discussions, given the number of volunteers involved and the dependence that hospices have on this resource as identified by Davis-Smith (2004). It can be argued, however, that these policies were developed with the NHS as the key focus and that this may explain the lack of consideration of volunteering. As outlined above, however, the NHS takes the involvement of volunteers very seriously, given the commitment in their revised strategy for Health Boards to achieve a volunteering quality standard. Indeed, Hawkins and Restall (2006) in their guidance for NHS organisations in England on the involvement of volunteers outline the benefits of volunteering to the NHS and identify that volunteers allow for a “more personal response” to patients and “better local ownership” (p2) of the service.

There are similar strands running through the policies of the governments of the four UK countries, with a broad general consensus of the need to widen access

and improve palliative care delivery to all patients regardless of diagnosis. Both the Audit Scotland review of palliative care (2008) and the Department of Health End of Life Strategy (2008) have recognised the significant work of hospices in the development of specialist skills and knowledge in palliative care and also in the delivery of specialist palliative care. Alongside this recognition is criticism of the adult hospice movement for being available only to a small and specific group of patients, mainly suffering from cancer but with very complex palliative care needs. This is in contrast to the children's hospice population where few children cared for have cancer, with the majority affected by a diverse range of complex, sometimes rare, life-limiting conditions.

The need to ensure the sustainability of services is another key theme running throughout palliative care policy. Whilst policy focuses on the need to increase access to good palliative care for all, this challenges hospices to consider the impact on their services and their future role in the delivery of this ambitious agenda. It is important with the focus moving to such an agenda, that the crucial contribution of hospices is not overlooked. The impact of volunteering on hospice sustainability, therefore, deserves serious consideration.

Having considered the issues surrounding the omission of volunteering from much of the palliative care policy development, comparison with volunteering policy may be helpful in understanding the wider context of volunteering in the UK and consider what, if any, impact this might have on hospices and their volunteering programmes.

1.3.2 Volunteering policy context in UK

Volunteering has also been an area of interest for UK governments in recent years. The focus has been on areas such as citizenship; the involvement of under-represented groups; corporate social responsibility; voluntary organisations increasingly undertaking work previously delivered by statutory organisations and the move to more formalised volunteering. This has had an impact on volunteering both directly and indirectly. As a result, more and more organisations are seeking to involve volunteers. However, it is important to consider these policies in the light of the reality of volunteering statistics in the UK. The following figures are for 'formal volunteering', which is defined by Rochester et al. (2010) as donating time without financial gain to benefit others in an organised way through organisations, groups or clubs. The 2007-2008 Citizenship Survey cited in Rochester et al. (2010) showed that 43% of the population of England was involved in volunteering, up from 39% in 2001. Recent figures from the Community Life Survey (2013) for formal volunteering indicated that it had risen by 5% during the quarter August to October 2012. This is in the immediate wake of the Olympic Games and the significant focus on volunteering during that time. It will be interesting to observe as to whether this increased interest in volunteering is sustained. In Northern Ireland volunteering had dropped from 29% in 2001 to 21% in 2007. However, in Wales the figure remained steady at around 40% in 2003. The 2009 Scottish Household Survey by the Scottish Government (2010) indicated that volunteering had dropped from 32% in 2006 to 29% in 2009. However, Volunteer Development Scotland (2013) suggests that formal volunteering has

remains reasonably consistent since 2007. Taking these figures as a whole for the UK, it would appear from the statistics that overall trends in volunteering have previously been at best static and at worst dropping. Whilst it is a welcome development to see some recent small upward trends now developing, only time will tell if this is sustained.

Whilst there were claims that the number of people volunteering during the recession increased, Hill (2011) suggests that these are not borne out through the statistical data on volunteering. This discursive paper, which draws upon published volunteering statistics, concludes that one reason for this may be the rise in unemployment, as it is known that the unemployed are less likely to volunteer. He asserts that if volunteering is to grow that this will require an investment of resources to provide support, not only to volunteers, but also those who are involved in their management. Hill's argument on the recession is clear, well reasoned and backed by statistical evidence from national survey data. However, Hill (2011) acknowledges that there is little known about volunteering and recession. His work would be further strengthened by more in-depth research involving a range of organisations to understand the impact of recession on volunteering. Anecdotal evidence from my own organisation and others would support Hill's study. Having experienced a significant rise in enquiries during this period, very few of these actually followed through to become volunteers. It is possible that people who do engage in volunteering whilst unemployed will be lost to organisations once they are able to find paid work once again. However, if their experience is valuable and rewarding, they may go on to support the organisation in different ways in the future. Evidence

from literature and practice, therefore, presents a picture of a fluctuating and fluid volunteer workforce. This must, therefore, pose a challenge for organisations so dependent on this resource both now and in the future.

In 2006 the England Volunteering Development Council set up a commission to look at the future of volunteering. As part of this work, Rochester's initial literature review (2006) of 113 international papers considered the impact of the changing society in which we live. He describes the impact of the ageing population; the retirement age increasing; couples having children later, if at all; grandparents caring for grandchildren; young people studying for longer and the range of leisure activities available to people. All these areas have the potential to reduce the time available to people for volunteering. What is not considered by Rochester is that, in addition to young people undertaking more studies, there is a need for them also to work in order to gain experience or to fund their education. Anecdotal evidence would suggest that this is a reality for many senior school pupils and students. In addition to the increase in retirement age, the pensions crisis may also mean that many people will have to continue to work for much longer than previous generations. This has the potential to further reduce the pool of prospective volunteers.

Howlett (2009), some three years later, echoes Rochester's (2006) view that volunteers have considerable choice today as to how to and where they spend their time. This is borne out by my own experience and that of colleagues involved in the management of volunteers. As volunteers have less time to give, we currently need more volunteers to support services previously

delivered by fewer volunteers. Rochester (2006) also considers the increase in the number of people living on their own, the lack of sense of community, increasing secularisation and the increasing popularity of electronic communication and networking as having an impact on volunteering. However, this may have significance to the hospice context as previously in 2004, Davis-Smith (2004), described the typical hospice volunteer as being drawn from an older age group with many from church and community groups. If younger people do not engage with hospices, this will have significant impact on hospice volunteering in the future.

More recently, the UK Government introduced the idea of the Big Society (2010). This was to be a programme of policies, the stated aim of which is to empower individuals and communities to make a difference locally and to society as a whole. The Big Society Overview (2011) identifies three key policy areas around communities, public services and society. The policy areas include encouraging a range of agencies, including charities and private companies to provide services at present provided by the statutory sector, in addition to encouraging individuals to get more involved in shaping society.

Whilst it could be considered that similar initiatives have existed previously, for example, the Active Communities project in Scotland (2001), this undoubtedly introduces a competitive element where charities may have to compete, not only to provide services, but also for volunteers. The Scottish Government's Volunteering Strategy 2004-9 (2004) asserts that it is in everyone's best interests for volunteering to become an integral part of Scottish society. It

promises to promote volunteering to younger people and to reduce barriers to volunteering to make it more inclusive. However, it makes no mention of what has for many years been the mainstay of volunteering in Scotland – middle to older age groups. The strategy also pledged to improve the management of volunteers. Five years on from this strategy, the figures for volunteering in Scotland had dropped 4% by 2009. As there has been no new volunteering strategy since 2009, it could be considered that volunteering may no longer be a priority for the government in Scotland. One could argue that as a result of changes in society, there is now a need for a new and refreshed strategy. Considering the Scottish experience, it is not clear how much government strategy actually influences volunteering. Questions must also be asked as to whether government policy can, or should influence the development of volunteering, which is based on the freedom and goodwill of individuals to make choices as to how to spend their time.

Gay (2001); Gaskin (2003); Davis-Smith (2004); Rochester et al. (2010) suggest that volunteers' expectations of their volunteering experience are not only changing, but are high. The profile of the volunteer making a regular commitment over many years to one organisation is changing and likely to continue to do so in the future. Many younger people are looking for short-term high impact experiences. This is borne out by my professional experience in recent years. If volunteer expectations are not met, they are unlikely to stay, their impression of the organisation will be poor, and their skills and expertise will be lost.

Given Gay (2001), Gaskin (2003), Davis-Smith (2004) and Howlett's (2009) views that people expect more today from the organisations they support than previously, volunteers could be considered to be taking on the role of 'consumers' of the organisation in which they choose to donate their time. Time-pressed volunteers are keen to ensure that they have the best possible opportunity and experience, with their time being put to good use. It is important that the implications arising from this are recognised by volunteer-involving organisations and that volunteer contribution and costs are given serious consideration alongside all other aspects of the service. This is especially important for those for whom service delivery and continuity are important to their client group, as it is in hospices.

1.3.3 Summary and conclusion

Throughout recent palliative care policy developments and discussions, it is of concern that one crucial element is so consistently overlooked - the role of the hospice volunteers. This is a significant omission considering the underpinning role of volunteers in hospice development and service delivery. Contrary to this is the focus of UK governments on the engagement and empowerment of communities, encouraging more people to volunteer, including currently under-represented groups, and improving standards of volunteer management. This is set within a context of scarcity of funding, static or falling volunteer numbers and increasing expectations from people who choose to volunteer today. As local charitable organisations, hospices are dependent on the contribution of their local communities for funding, staffing and volunteering or, indeed, for their very survival.

The changing policy environment, coupled with shifting volunteer expectations, is likely to have a considerable impact on hospices as they compete to attract and to retain volunteers - a key element of their workforce, not to mention the holistic care which they seek to provide. Yet findings from the literature, coupled with practitioner experience, would suggest that there is no research and little discussion at a strategic level in the hospice movement of voluntarism and its role in the future and sustainability of hospice care. This will be further explored in 1. 4.

1.4 Hospice Development in the UK - the Influence of Volunteers

"If you would understand anything, observe its beginnings and its development".
(Aristotle)

This section will explore the establishment of the UK modern hospice movement and the role which volunteers have played in this. It will then consider the relationship between volunteers and their influence on organisational development, and the link between volunteers and hospice sustainability. It will consider this in the context of both adult and children's hospices.

1.4.1 Early beginnings

Clark (1998) and duBoulay (2007) describe the beginning of the modern adult hospice movement in the UK, recognising Dame Cicely Saunders as the founder. She established St Christopher's Hospice which opened in Sydenham, London in 1967. Children's hospices, however, are a much younger specialty. Worswick (2001) describes the work of Sister Frances Dominica in the founding of the first children's hospice Helen House in Oxford in 1982. Clark's (1998) discursive paper has an incontrovertible evidence base, drawing upon archives related to the development of hospices, letters from Dame Cicely Saunders and biographical material of her life. However, this paper focuses clearly on her professional and personal approach to the development of hospice care. What is missing is the consideration of the voluntary nature and ethos of her work and the influence that this approach has on organisational development and culture. Again, Worswick (2001) considers

the history of the development of Helen House, the first children's hospice, and this key work would have been strengthened by discourse on the voluntary dimensions of the organisation.

These first hospices initiated two 'movements' which have seen the numbers of hospices grow and develop throughout the four countries of the UK. A table of key adult and children's hospice developments is outlined in Table 1.7.

Table 1.7: Key hospice developments

Date	Development
1967	St Christopher's Hospice opened in London
1969	St Christopher's Hospice Home Care Service starts
1971	St Luke's Nursing Home – hospice opened in Sheffield
1975	First Hospice Day Care Service opened at St Luke's Hospice
1982	Helen House opened – UK First Children's Hospice
1984	Help the Hospices is founded: a UK umbrella charity supporting hospices
1987	Palliative Medicine recognised as a speciality in UK
1992	Children's Hospice Association Scotland formed. The first and only provider of children's hospices in Scotland.
1998	Children's Hospices UK (now known as Together for Short Lives) founded: – an umbrella organisation supporting children's hospices and palliative care in UK.
2010	Association of Paediatric Palliative Medicine founded in UK

Based on Clark, Small, Wright, Winslow and Hughes (2005)

In attempting to consider the voluntary context more fully, it is interesting to consider why people became involved in the early days of hospice development. James and Field (1992) identify hospice development as having arisen from a religious basis, a sense of 'calling' from those who founded services and the on-going development of networks of professionals who

advocated for and shared expertise around good end of life care. This work has a good evidence base, drawing upon archival and biographical material and a review of literature. However, whilst James and Field (1992) as long ago as the 1990's conclude that hospices have become mainstream, bureaucratic organisations, there has been no exploration as to whether the voluntary component has played any role in moderating this.

Clark, Small, Wright, Winslow and Hughes (2005) provide strong evidence of the existence and integration of volunteers in the founding, history and development of hospices. The work of Clark et al. (2005) is based on ten years of research, gathering data from the records of 100 hospices in UK and Ireland. Additionally over 200 interviews were undertaken with a diverse range of people involved in hospices in the UK and beyond. Whilst this work is clearly a very robust and important record, it could be considered to be subjective and incomplete as it depended on the individual's personal recollections and perceptions. However, this is recognised by the authors. Despite the strength of this work, the strategic role and importance of the volunteer contribution both to financial and people resourcing is not clearly expounded.

As outlined above, there is evidence to suggest that people became involved in the early modern hospice movement in the UK because of a belief in the vision and values. All were motivated to make care better for those at the end of life (James & Field, 1992; Clark, 1999; Clark et al., 2005; Worswick, 2001). Not all hospice founders, however, came from a religious or professional background. Many were from an individual or group of individuals who identified a gap in

service provision. For example my own organisation, Children's Hospice Association Scotland, was started by a group of parents who all had children with life-limiting conditions. At that time there was no children's hospice in Scotland and these families were travelling to England to receive much needed hospice care and support. In order to address the gap in service provision, they started a hospice service for children in Scotland. It was clear from my discussions with parents over the years that these founding parents all shared a passionate belief in the values of children's hospices. Their motives were also altruistic, in that their focus was not solely in making a difference to the lives of their children, but of others in a similar situation.

Whilst some literature regarding the early beginnings of the hospice movement recognises the involvement of volunteers, it overlooks the influence arising from the voluntary nature of hospice founders on the ethos and culture of the organisations subsequently created. It recognises the motivations of founders but fails to link this with volunteer motivations. These founders clearly fit the definition of volunteering from The Scottish Government Volunteering Strategy (2004) as outlined in 1.1.2. They embody the very essence of voluntarism in terms of the freedom to envision, innovate and experiment; to involve local communities in addressing areas of common concern, whilst aspiring to making life better for others. Because this dimension is largely missing from the literature, an important element of the voluntary nature of hospice organisational development and uniqueness of culture is missing.

1.4.2 Volunteers and their role in hospice organisational development

The literature, whilst recognising the involvement of volunteers in the development of hospice organisations, does not consider the changing role and influence of volunteering at different stages of development. However, Fisher, Rooke and Torbert (2003) give a valuable insight into what happens in organisations during different the phases of evolution. The context of their work mostly relates to large commercial organisations. I considered their theory alongside the findings from the literature review, and drew from my own professional experience, to adapt their framework. I applied this to hospices to demonstrate the changing influence which volunteering has on the development of the organisation. Describing nine key steps of personal and organisational stages of development, Fisher et al. (2003) assert that there are few, if any, examples of organisations reaching the final two stages. The first seven organisational stages, however, give an alternative insight into hospice development and allows further exploration and explanation of the roles of volunteers as outlined in Table 1.8. These stages defined by Fisher et al. (2003, pp. 81-82) are: “Conception; Investments; Incorporation; Experiments; Systematic Productivity; Social Network and Collaborative Enquiry”.

In applying this framework to hospices, it can be seen that the influence of volunteers changes from dominant to less dominant throughout the stages of development. Hands on volunteers have most influence in Stages 1 and 2, with volunteer trustees taking over this role once the charity is incorporated somewhere between Stage 2 and 3. Volunteers from Stage 1 and 2 may of course become trustees in Stage 3 thus developing and formalising the

responsibility of their initial role. The role of trustees then becomes dominant in Stage 3 and 4 until the first key staff appointments and development of initial strategy. I have assumed that it is likely that this applies to most independent UK hospices.

Table 1.8

Comparing Hospice Development with Fisher, Rooke and Torbert's Organisational Stages of Development (2003, p.81)

Fisher, Rooke & Torbert's Stages of Organisational Development	Fisher, Rooke and Torbert's Characteristics	Hospices	Dominant/ Influential Groups
1. Conception	Dreams of creating new organisation	Hospice need/desire identified by individual/s/community	Hands on volunteers
2. Investments	Spiritual, social network and financial investments	Group constituted, networks establishing, fundraising begins.	Hands on volunteers Volunteer Trustees
3. Incorporation	Products or services actually rendered	Building built/ initial professional staff recruited	Volunteer Trustees Staff Hands on volunteers
4. Experiments	Alternative strategies and structures tested	Defining hospice staffing, care/ funding and fundraising strategies. Patients receiving care	Staff Volunteer Trustees
5. Systematic Productivity	Single structure/strategy institutionalised	Expansion of services/ quality standards Outcomes as measures of success	Staff Volunteer Trustees Hands on volunteers (volunteer value)
6. Social network	Portfolio of distinctive organisational features	Clear marketing of services. Development of strong alliances/ partnerships with other organisations e.g. statutory and voluntary providers	Staff Volunteer Trustees Hand on volunteers
7. Collaborative Enquiry	Self amending structure rules matches dream/mission	Interactive development of unique, changing structures appropriate to hospice and current situation e.g. new services/mergers/social enterprise initiatives. Review of mission and strategy.	Volunteer Trustees Staff Hands on volunteers

Based on " Parallels Between Personal and Organisational Stages of Development" Fisher, Rooke and Torbert (2003, p. 81)

Whilst hospices initially set out to challenge conventional approaches to the care of the dying, as early as the 1990s, James and Field (1992) considered that they had become part of mainstream health care. They argue that the need for public and professional accountability increased as hospices established structures and standards of care. Indeed hospices today exist in a very regulated environment and it could be argued, therefore, that external influences were the cause of this 'mainstreaming'. Alternatively this could be considered to be a factor of organisational development as shown in Stage 5 of Fisher, Rooke and Torbert's Stages of Organisational Development where they consider that "political viability of a product or service, as measured in quantifiable terms (is) the overriding viability of success" (2003, p.82). The Palliative Care Funding Review (Hughes-Hallet, Craft & Davies, 2011) indicates that hospices receive in the region of 34% statutory funding. They do, therefore, need to consider the 'political viability' of their services as a high priority. Whilst it is undoubtedly true that independent hospices have come to be seen as a key component of health care today, James and Field's (1992) view may be challenged by the fact that independent hospices still have freedom to innovate and develop unique services in response to the needs of their patients and local community.

The staff role remains most influential from Stages 4 until 7, where major new developments or mergers once again bring volunteer trustees into the dominant frame. What this framework does demonstrate is the significant and changing influence, which volunteers have on the developing hospice organisation. Further exploration of this concept might provide opportunities to reframe

current thinking around volunteer involvement in hospice organisational structure and development.

Evidence from the literature would give some support to the framework outlined in 1.8. Scott et al. (2009) assert that many, if not all hospices can trace their origins back to volunteers. This is borne out by Clark et al. (2005) in their oral history of the hospice movement where evidence from the personal accounts of those interviewed confirms involvement of volunteers throughout the history and development of hospices. Sallnow (2010), in a narrative synthesis of literature, which included 126 international papers, asserts that volunteers are so influential in, and inextricably linked with, the development of hospices that it is unlikely that hospices would have continued to proliferate and flourish without this involvement. This study seemed to be based on robust methods of analysis, from which Sallnow (2010) has introduced a new conceptual model of volunteering in palliative care, which demonstrates the elements which may affect volunteers and volunteering impacts within an organisation, including structures and management. However this is derived from the perspective of the volunteer's experience and the reciprocal influence which volunteering may exert upwards on organisational culture and structure does not appear to have been fully explored, especially given the role of trustees in hospices. Stage seven of Fisher, Rooke and Torbert's Stages of Organisational Development (2003) as applied to hospices (Table 1.8) describes the ongoing development of the established organisation, which is adapting to changes in the wider world, presumably in order to remain effective and sustainable. It is important therefore to consider issues affecting organisational sustainability before looking

specifically at the relationship between volunteering and hospice viability.

1.4.3 Organisational sustainability

In exploring sustainability, particularly in relation to voluntary organisations, it is interesting to note that most discussions focus purely on the subject of finance. Theodosopoulos (2011), in considering the financial sustainability of hospices in England suggests that current models are vulnerable. His reasons are based on current policy, which increases expectations on hospices to care for a wider catchment of people with terminal illnesses other than cancer. Theodosopoulos also cites the expected growth in cancer as a result of an ageing population. Calanzani, Higginson and Gomes (2013) estimate that by 2023 deaths from cancer will rise by 30% for men and 12% for women which is a significant increase. Additionally Theodosopoulos (2011), identifies regulatory burdens and the uncertainty of donated, statutory and invested income, legacies, and grants. He concludes that in England, the Government's end of life care strategy depends on the reliability and sustainability of hospice economic models which he believes are at risk of being unsustainable.

Maddocks (2011) suggests that whilst effective financial reporting is important to the future success of charities, this does not give the full picture of the wellbeing of the organisation. He asserts that charities, which depend on financial reporting as an indicator of success, risk missing other key elements which determine sustainability in the longer term and concludes that "sustainability reporting" is missing from the current charity reporting

procedures. Herman and Renz (2008) conclude that organisational effectiveness is multifaceted and cites board effectiveness; management practices (not necessarily best practice); and stakeholder involvement, including volunteering, as important areas. They recognise that volunteer and community involvement are difficult to measure and that organisational outcomes are not necessarily indicators of effectiveness. It is important to consider further the relationship between volunteering and hospice sustainability.

1.4.4 Volunteers and hospice sustainability

Guriguis-Younger, Kelley and McKee (2005) claim that volunteers are not only vital to, but are also the most constant component of palliative and end of life care. Whilst their paper, is based on personal reflections, rather than an evidence base, there is support for their view both within the literature and from anecdotal evidence. Therefore, having considered issues of organisational sustainability and volunteering from an organisational development standpoint, it is worth exploring the continuing role of volunteering in UK hospices today and consider the relationship between volunteering and hospice viability. In order to achieve this it is necessary to understand:

- what motivates people to volunteer;
- organisational approaches which influence volunteering programmes;
- volunteers and their impact on patients and families;
- volunteers and their economic impact on hospices;
- volunteers and governance.

Volunteer Motivation

Volunteer motivation is a key element of sustainability: the motivation to enquire, to follow through, to undertake training, to make a commitment and to remain with an organisation are the foundations on which any volunteer programme is built. There are many reasons why people volunteer. Rochester, et al. (2010) group these into six main areas of motivation. These include the desire to: help others; develop or share existing skills, gain experience to help gain employment or change career, be part of something or make new friends/gain approval; mitigate guilt about having an advantaged life and support personal development by increasing confidence and self esteem. These are fairly traditional, accepted areas of motivation. An earlier study by Claxton-Oldfield, Jeffries, Fawcett, Wasylkiw, and Claxton-Oldfield (2004) found similar motivations but suggested that palliative care volunteers are driven more strongly by altruism. However, we have to be mindful that this data was based on views of only 15 palliative care volunteers. Whilst these were then tested on a further 113 volunteers the study focused mainly on care-giving roles. It would be interesting to explore whether these findings hold true for hospice volunteers involved in non- care roles such as fundraising and administration.

Some years previously, Wilson (2000) challenged accepted views on motivation in his sociological exploration of volunteering constructs. Wlison's study is based on an extensive review of literature and makes strong arguments to question simple descriptors of volunteer motivation. He argues that the impact of environment, in terms of organisation and social influences, on volunteer motivation is given little consideration. Hustinx, Cnaan, and Handy (2010)

support Wilson's view and suggest that motivation to volunteer is complex and constructed differently within sociological and psychological frameworks. They assert that the reasons which prompt people to volunteer may include both selfless and selfish elements. The focus of their work is a complex synthesis of volunteering theories in an attempt to provide researchers with signposts to under-researched areas. Whilst their conceptual model has achieved their research aim, on the basis of my professional experience, I would suggest that is perhaps detrimental to consider motivations as selfless or selfish as they can influence staff attitudes to certain volunteers. People are frequently drawn to volunteer in hospices because of personal experience of hospice care or as a gesture of 'thanks' that they and their families have not had need of such care. However, once people have been motivated to become volunteers, sustaining this interest and commitment should become a key organisational consideration. What is often overlooked is the impact of hospices' organisational approaches on the volunteers and their needs.

Organisational approaches influencing volunteering programmes

Having considered volunteer motivations, it is important to explore some organisational perspectives on volunteering. Organisations may involve volunteers for many different reasons. McCurley and Lynch (1998) suggest that these may include developing reciprocal links with local communities, complementing the skills of paid staff, raising funds, using volunteers where scarcity of finance does not allow for paid staff; maximising cost effectiveness, making services more personal – adding a different dimension to services or

increasing speed and flexibility in responding to changing or emergency situations. McCurley and Lynch's suggestion of substituting for paid staff amidst scarcity of resources is a contentious issue today, but does happen. Hospices involve volunteers for many of the reasons evinced by McCurley and Lynch (1998), however recent discussions at hospice volunteer managers' forum suggest that an increasing focus for the development of volunteering is cost saving.

Whilst there are many warm statements about the contribution of volunteers, Hoad (1991) considered that few organisations were publicly explicit about their reasons for involving volunteers, and their expectations of them. The aim of Hoad's qualitative study was to examine the roles and boundaries of volunteers in UK hospices. Findings were based on a postal survey of 401 volunteers from 33 UK hospices. They provide convincing evidence to support his conclusions that it is difficult to make comparisons as volunteer roles; autonomy and influence were so varied. He also asserts that staff/volunteer boundaries are unclear. It could be argued this lack of clarity and consistency is as a result of a lack of strategic consideration of the purpose and role of volunteers within hospices. Twenty years later, this does not seem to have changed.

To be an effective part of any organisation, a volunteer programme needs to be well planned, structured and resourced, as well as consistent and sustainable, especially in a hospice setting where significant time is invested in the training and support of volunteers. A working paper of the Commission into the Future of Hospice Care (Help the Hospices 2012b) suggests that volunteers are key to

hospice strategy to enable them to increase both the influence and scope of services. Hospices must therefore understand what will attract and retain volunteers. Of concern, however, are findings of a review of governance in hospices undertaken by the Charity Commissio (Help the Hospices 2006b). Based on 48 visits to hospices in England, between 2001 and 2006, they found that approximately 20% of hospices were found to be inadequate in their approach to managing staff and volunteers. Whilst not all the reasons for this are clear, one area highlighted was the inadequacy of the distinction between staff and volunteers and the risk of volunteers being considered, therefore, to have employment rights. Although this report is based on hospices in England only, my professional experience would lead me to suggest that hospice organisations in other UK countries have similar structures and these findings may have wider applicability, even some years later. A more recent study by Morris, Wilmot, Hill, Ockenden and Payne (2013) explored issues facing volunteer involving organisations in end of life care. They identify a number of challenges for such organisations in managing the increasing demand for services, reduction in funding coupled with a fluctuating pool of volunteers and changing expectations of volunteers. They assert that volunteer managers must be sensitive in their handing of the unique role of volunteers within the team and also the balance between diversifying the volunteer workforce and managing the drive towards increasing formalisation of volunteering. They conclude, however, that volunteers could become involved in more creative ways with end of life care and increase engagement with local communities. This study was a comprehensive review of international literature on volunteering and end of life care and supports findings from earlier research.

However, it could be strengthened by clearer recommendations for practice.

If volunteering is to be successful, organisations must also understand and address the reasons which prompt people to volunteer with them. Gaskin (2003) asserts that if organisations are to sustain a volunteering programme, then volunteers' aspirations and motivations must be met and matched. This qualitative study, whilst based on focus groups involving 26 volunteers with a diverse range of volunteering experiences, presents a convincing framework for organisations to ensure that volunteers are not only attracted to, but go on to stay with organisations. According to Gaskin (2003) organisational structures and management approaches must take account of volunteer needs and aspirations and concludes that a range of management approaches and structures are required to ensure success. This is supported in a later study by Guirguis-Younger and Grafanaki (2008). They held focus group interviews with 17 volunteers from three organisations and consider that for volunteering to be sustainable, there must be symbiosis between organisational and volunteer needs. From my professional experience I would agree with these findings, however these studies would have been strengthened by involvement of the staff perspective.

There is, however, some evidence from a staff perspective from Zimmeck's (2001) earlier study which evinces similar views to those of Gaskin (2003) and Guirguis-Younger and Grafanak(2008). Whilst the research methodology is not detailed, Zimmeck's study (2001) involved volunteer management practitioners. In considering the contradiction of falling volunteer numbers when the profile of

volunteering is high, Zimmeck (2001) concludes that modern volunteer management models, which have been adopted from industry, may not be appropriate for volunteers.

This may be a factor in explaining why volunteers do not always feel well organised and supported by organisations. Gay (2001) found that a significant number of volunteers reported that their volunteering could be more effectively managed. She concluded that there was a need to ensure improved professionalism of volunteer management through the development of a professional association. The evidence base is strong, drawing on the views of volunteer managers, senior managers, volunteers and professional associations. The resulting arguments are persuasive. Some year's later, Davis-Smith (2004) also found that hospice volunteers reported that they did not always feel valued and believed that their work could be better organised. Davis–Smith's (2004) research challenged the sustainability of hospice volunteering and also recommended that hospices needed to adapt practice to introduce new roles and new people, to reduce bureaucracy and invest in management and support. The evidence is drawn from two surveys of Hospice Volunteer Managers with 153 and 138 responses respectively. Responses were also received from 661 volunteers. The evidence base is significant and likely to be representative of hospices, however evidence from hospice staff, who were not involved with the management of volunteers, would have enriched and further informed the research. It is important to see whether this picture has changed in 2013.

Barron (2008) undertook a more recent study into the progress of volunteer management since 2003. The study based on interviews with 20 hospice Voluntary services Managers (VSMs), concluded that hospice volunteer management has evolved to respond to changing society and volunteer expectations. However, some concerns which arose in Davis-Smith's research (2004), such as lack of recognition of the management challenge, and of volunteers as an integral part of the team, were still evident. Barron implies that volunteer criticisms of poor management in Davis-Smith's study (2004), are being addressed by VSMs, but there is no evidence to support this. I know from professional networking meetings and conferences that there are now many hospices with high quality, innovative volunteering practice, however, evidence from Gaskin (2003), Davis-Smith (2004), Addington-Hall and Karlsen (2005a and 2005b) and Barron (2008) would suggest that hospice attitudes towards volunteers have changed little. This is of concern, given the findings of Andersson and Ohlen's study (2005), which concluded that volunteers needed to be recognised fully as part of the hospice team in order to feel valued.

This theme is further explored and developed in an influential, in depth study of 19 UK hospices by Addington-Hall and Karlsen (2005 a). The purpose of the study was to explore the views of volunteers and staff on hospice care and their experiences of working in these organisations. The sample size was representative of the whole in terms of size and geography, and therefore likely to have wide applicability. They concluded that volunteers and staff were not always in agreement about developments although they largely shared the vision of key elements of care. This study highlights the relationship between

volunteers and hospice sustainability and suggests that hospices need to take account of volunteer opinions on key issues as they may reflect the views of the public. She asserts that hospices must continue to engage in discussion with volunteers to ensure that they not only understand, but support developments in hospice care, otherwise the risks to funding and volunteering may be significant. Worryingly, in a second paper exploring experiences of working hospices, Addington Hall and Karlsen (2005b) identify that only 12% of volunteers felt that they had influence.

A later report arising from the Commission on the Future of Volunteering (2008) recommended that organisations needed to modernise their aproach to volunteering and to consider new and creative approaches. The report was the outcome of a major project that gathered oral and written evidence, from those involved in and with volunteering and also from people who were not volunteers. This is an important and influential piece of work, and whilst focused mainly in England, I believe that the findings still may be applied to the wider UK and certainly have relevance to hospices in terms of considering their organisational approach to volunteering.

Volunteer Impact on Patients and Families

Having considered hospice approaches to volunteer motivations and the influence of management approaches, what is not so clear are the expectations and experiences of patients and families of being supported by volunteers as there is little research in this area. Gurgius-Younger, Kelley, and McKee (2005),

in a discursive paper based on personal reflections, explore the concept of volunteers as integral members of the hospice team rather than casual helpers. They argue that the move towards professionalisation may benefit organisations in terms of boundaries, management and funding but conclude that this will have a detrimental effect on the volunteering experience and on their relationships with patients. Volunteers, they suggest, are recognised as bringing a unique, personal and "human" approach in reaching out to those at end of life in increasingly medicalised environments. Whilst this paper may not be based on evidence, I would support these conclusions from professional experience. Findings from a recent research study by Naylor, Mundle, Weaks and Buck (2013) suggest that volunteers greatly enhance the role of paid staff and improve the patient experience of care. The study suggests that volunteers also build strong links between services and communities. They see many opportunities for volunteers in the future in changing and developing health and social care. However, they identify a number of challenges ahead suggesting that many organisations have no strategic view of volunteering and do not recognise the key role that they may play as part of the workforce. They believe also that volunteering is inextricably linked to the sustainability of services in the future. This qualitative study used focus groups and scenario analysis to gather data. Respondents had a varied range of backgrounds, including volunteers, patients, service providers and commissioners and scenario analysis. The approach is robust and the compelling evidence is strengthened by this diverse group of respondents.

Describing the relationship between patients and volunteers as a mystery, Gurgius-Younger, Kelley, and McKee (2005), assert that there are many

unknowns about the experience of the volunteer patient relationship from both perspectives. Their assertion is that as the focus of professionals has moved to a more medical model of care, volunteers may have an even more important role to play in bridging the gap by bringing in a different dimension of human compassion and companionship. As early as 1997, Corner and Dunlop (1997) evinced a similar view of a medicalised model of care and recommended that the approach to care needs to be reconsidered with a view to "achieving the end sought by the sufferer, and not those determined by the practitioner or clinician" (p300). Faulkner and Davies' study (2005) is NHS based and suggests that volunteer support may have a beneficial impact on patients. The author urges caution in generalising his findings. However, a study by Scott (2006a) into volunteering in a children's hospice found families' experienced significant benefits from the additional support which volunteers provided. This reduced families' isolation and provided access to additional services. This was based, however, on evidence from only 12 families. A recent study of volunteering on children's hospices by Burbeck, Low, Sampson, Scott, Bravery and Candy (2013) found, that volunteers were involved with children, young people and their families. However, whilst there was some evidence of volunteers being involved in hands on care and in end of life care, they found that fewer volunteers had contact with children, young people, and families than in adult hospices. Burbeck et al. (2013) suggest that children's hospice services may be more reluctant to involve volunteers than their adult counterparts. Their study also identified a hesitance to involve volunteers in family homes and suggest that this might be due to reluctance both on the part of hospice services and patients. This study provides interesting and valuable research insight into

volunteering in children's hospices. Based on responses from volunteer managers in 30 children's hospice services it is likely to have wide applicability to the children's hospice sector as a whole. However, it would have been interesting to have data from staff and parents in order to better understand children's hospice attitudes to volunteers as Scott (2009) in her chapter on volunteering in children's hospices, suggests that the involvement of volunteers within the multi disciplinary team adds to the holistic nature of care.

Volunteers and their economic impact on hospices

Another factor in the relationship between volunteers and hospice sustainability is their impact on the hospice economy. Gaskin (2003) estimated that individual volunteers annually contributed approximately £1,500 of work, which cost £200 of management time. She concluded that applying this widely would suggest that annually, 90,000 hospice volunteers donated in excess of 18 million hours with an economic value of £133 million, with only £16.7 million invested in supporting and managing this resource. These figures must be read with caution as they were extrapolated from a sample size of only three hospices. However, a subsequent pilot study undertaken by Help the Hospices (2006a) involving 59 hospices concluded that hospice costs would increase by 23% if hospices had to pay for work undertaken by volunteers. The study also suggested that of each £5 of hospice input, £1 was from volunteer involvement, and £1 from the NHS. Caution is required in considering these statistics as the methodology indicates a lack of consistency as different methods of apportioning value to volunteer time were used. Despite this, it may still be

deduced that volunteers have a significant economic impact on hospices and Scott (2007) suggests that it is important that hospices do not overlook this. One year previously, Wilson et al. (2005) suggested that volunteers may be key to economic stability of organisations, through raising funds and providing additional cost effective services. Wilson et al. (2005) recognised, however, that there was a lack of evidence-based research to support their view.

In considering the difference in approach to volunteers and to donors, Evans and Saxton (2005) in their discursive paper, suggest that organisations need to approach volunteering in the same way as they do with fundraising. They assert that organisations invest time and resources in attracting and keeping donors because of the long-term financial benefit. However, they fail to do this with volunteers. This idea is very relevant to hospices, given the high numbers of volunteers involved in all activities, and also the economic benefit of their donated time.

Volunteers and governance

The last and often least considered link between volunteers and hospice sustainability is that of governance. All independent hospices are governed by volunteers in their role as trustees. These positions carry significant responsibility as outlined by both Help the Hospices (2005) and Dyer (2008) in their guidance for trustees. They identify significant legal obligations for these volunteers in setting the strategic direction of their organisation, and ensuring that resources are used effectively and safely for the wellbeing of the

beneficiaries. It is interesting to note that volunteers as trustees are also employers of paid staff, frequently with line management responsibility for the Chief Executive. Despite the significance of this group, according to Turner and Payne (2008), there is little if any research about these volunteers and this has highlighted the need for greater understanding of this group. Their survey, based on 610 responses from hospice trustees in the UK described a lack of diversity in the make up and background of volunteers, and good support but poor recruitment and review strategies. A second qualitative study by Turner and Payne (2009) based on semi-structured interviews with 20 hospice trustees concluded that these volunteers are challenged by the rapidly changing landscape impacting on hospice care. These findings illustrate not only that volunteers as trustees carry significant legal responsibility but also that they may be ill-equipped to cope with a changing and challenging environment. Wise (2001) would support these findings. In a review of academic literature he concludes that charity governance leaves much room for improvement and asserts that the reasons for this lie in the difficulty in finding the right people to act as trustees. He suggests that there is no shortage of suitable people and charities must, therefore, look at their recruitment methods. I would support this view and find the contrast between the recruitment and review of trustees and the formal management strategies in place for other hospice volunteers, of concern. These may have implications for the future effectiveness and sustainability of hospices in a changing world.

Despite the key role of volunteers in hospice governance, there can be many

barriers to volunteers undertaking meaningful roles in end of life care for hospice patients. This is an interesting tension whereby hospices will entrust their governance and future strategic direction to volunteers, but restrict the involvement of others to less meaningful roles. The many boundaries set in place to restrict volunteer activity are often done in the name of protecting patients. However, Hoad (1991), McCurley (1998) and Pastor (2010) suggest that staff feel that their jobs may be threatened by volunteer involvement and this results in their reluctance to embrace volunteering.

Hoad's study (1991), previously discussed in 4.3.2, asserts that paid staff had control over what and how much information should be given to volunteers. He also noted claims that volunteers who may have specialist skills may threaten the "professional power and knowledge base of paid staff". Contradicting these findings, Scott (2006b) in a study of UK children's hospices' experiences of volunteering, identified that only a small number of staff were wary of volunteers. Whilst this was a small study it drew from 18 children's hospices across the UK and is likely to be fairly representative. Similarly, Pastor's study (2010) found that some staff have negative views of volunteers, with a few feeling that they posed a risk to jobs. It is not clear what percentage feel this way. The author suggests caution in applying his findings widely as this was a small study. He used a case study approach, however, and generated a depth of data. My professional experience leads me to believe that there are some staff who do feel threatened by volunteers, but these may be increasingly in the minority.

Having considered the link between volunteering and hospice sustainability, it is worth considering whether the approach to volunteering in UK hospices is itself capable of being maintained. In their discussion on volunteering in society, Rochester et al. (2010 p25) describe the 'dominant paradigm' as one where organisations involve volunteers for the purpose of delivering a service to others. Hospices volunteering models undoubtedly fall into this category, being very traditional in their approach to volunteering with volunteers being formally managed by paid staff through hierarchical structures. Gay (2001); Gaskin (2003); Davis-Smith (2004); Rochester et al.(2010) challenge the sustainability of this type of model, as they assert that volunteers have changing expectations of the organisations where they volunteer.

Recently the UK has shown interest in models of palliative care volunteering from other countries such as the Neighbourhood Network volunteering model in Kerala. Kumar and Matthew (2005), in a discursive paper, describe this approach where the initiation of care is made by the volunteers living alongside patients in the community. Kumar and Matthews (2005) suggest that this is both cost-effective and sustainable as a model, especially in the developing world. A significant study was undertaken by Leadbetter and Garber (2010) into death and dying in the UK. Compelling and extensive evidence was drawn from archives, polls and field research and has been the catalyst for discussion into the future of end of life care in the UK. Leadbetter and Garber (2010, p.15) suggest that the UK must develop a "properly trained volunteer network support modeled on Kerala's Neighbourhood Network for Palliative Care".However, further research is required to explore the cultural and societal influences of such a model and consider the conditions which would be required in the UK in

order for such a model to work.

1.**4.5 Summary and Conclusion**

There is clear evidence from the literature that the impetus for the development of hospices arose from significant concern amongst key individuals about the quality of care for the dying amidst a changing society and fast developing NHS. It can be deduced from the literature that those initiating the development of hospices did so in a voluntary capacity driven by the belief that they could make life better for those at the end of life. Findings also indicate that volunteers played a key role not only in the initiation but also in influencing the ongoing development of the independent hospice movement in the UK, and the structure and direction of individual organisations. However, some literature suggests that children's hospices may involve volunteers less readily than adult hospice services. There is evidence to support a continuing dependence on volunteers today, in order to provide the range and quality of services to those for whom they care. Statistics show that volunteers make up a large proportion of people who work in hospices, It can, therefore be deduced that they play a significant and changing role throughout the life and development of the organisation. It can be concluded from the literature, however, that whilst volunteers have a range of motivations for volunteering, organisational attitudes and structures often inhibit hospice volunteers feeling a valued and integral part of the team.

Hospice volunteering, however, must not be considered in isolation and should be seen in the context of the wider landscape of volunteering and societal

changes. Evidence suggests that that the formal, hierarchical models of volunteering found in hospices today, may no longer meet the changing expectations of the 21st century volunteer. Volunteers make many contributions to hospices. Drawn from the surrounding area in which the hospice is located, volunteers enable strong, reciprocal links between hospices and their local communities. Findings from the literature review indicate that volunteers also have a key role to play in supporting patients and their families by bringing a social dimension to an increasingly medicalised approach to end of life care. Volunteers not only raise funds, but their contribution multiplies the skills of paid staff. This time donated by volunteers, allows hospices to offer a wider range of services and a more holistic approach to care, whilst making a significant contribution to the hospice economy.

This voluntary dimension, and the fact that hospices are governed by volunteers, must surely influence strategy, culture, patient experience, development and economy of each individual hospice. Yet there is little evidence from the literature to suggest that the strategic importance of volunteers is recognised, not only in hospices but also in the wider health and social care sector. This lack of recognition of such a significant proportion of the hospice workforce, results in only a partial view and explanation of the development and culture of hospices. Taking all of this into account, there is evidence to suggest a strong link between volunteers and hospice sustainability. It is vital, therefore, that hospices consider the strategic role and influence of volunteers and consider their part in the ability to maintain and deliver services in the future.

1.5 Towards a Theory of Volunteering and Sustainability

"Whenever a theory appears to you as the only possible one, take this as a sign that you have neither understood the theory nor the problem which it was intended to solve." – Karl R. Popper (1972)

1.5.1 Implications of findings

This review of literature sought to focus on volunteering in the UK independent hospice movement and to consider the relationship between volunteers and hospice sustainability. Findings indicate that whilst there is significant literature on volunteering in hospices, there is a dearth of research in terms of their influence on hospice development, strategy and sustainability. Davis-Smith (2006) asserts that whilst there has been much research carried out in the field of volunteering, there has been little attempt to develop and test theories in order to understand the increasing evidence base . He states: "we know a lot about people's motivation to volunteer and the size and shape of the volunteering sector; but we know very little about the underlying causes and meaning of voluntary action" (p120). This would be my experience of volunteering within the hospice sector. We do understand why people are motivated to volunteer in hospices; we understand the roles they undertake; yet we seem not to be able to fully integrate volunteers into the hospice team and to use their skills to the full. In applying Davis-Smith's view (2006), I would suggest that we still have much to learn about the "meaning of voluntary action" in hospices. It is clear that volunteering in hospices is experienced and interpreted differently by trustees, staff, patients, families and hands on volunteers. This is explained in Dixon's book on organisational learning (2000)

by her concept of meaning structures. She considers that each person learns by understanding his or her experience, and that this is specific to the person concerned. She refers to these as “meaning structures” (p17). Unless volunteer meaning structures are shared and understood by others and the organisation itself then there will continue to be little comprehension of the impact and influence of volunteering relationship to the hospice. Mintzberg, Ahlstrand and Lampel, (1998), in their book on strategy development, liken this to six blind men encountering an elephant. None can see the whole beast and each interprets a part of the animal as something quite different. There is some evidence within the literature to suggest that this analogy could apply to volunteering in hospices, where volunteers and their influence is perceived differently by volunteers, staff, and possibly patients. This lack of collective understanding of the meaning of volunteers to hospices might explain the lack of recognition of the strategic influence of and planning for volunteering. Through my proposed research into the link between volunteers and hospice sustainability, I hope to address these issues and to explore the meaning of volunteering, to independent hospices in the UK in terms of sustainability. A first step is to construct a theory synthesized from the findings of the literature review and subsequently to test this in practice. As part of this process it is necessary to consider the key findings from the literature about the contexts within which volunteering in hospices exist, namely, palliative care and volunteering policy, the development of hospices, the current trends in volunteering in the UK and their subsequent impact on hospices. The key themes, which have emerged from the interrogation of the literature are summarised below:

- Governments throughout the UK are promoting the development of palliative care with implications for increased demand on hospice services.
- Recent palliative care policy development takes little account of the role of volunteers.
- Governments are promoting both community involvement and volunteering in general, which will result in increasing competition for volunteers amongst organisations.
- Hospice funding is uncertain and the economic climate challenging, resulting in organisations having to achieve more with less.
- The number of people volunteering in the UK in recent years has been at best static, and at worst falling and it is too early to know if the recent upturn following the Olympic Games will be sustained.
- Prospective volunteers have many opportunities as to how to spend their time and have higher expectations of their volunteering experience.
- The role of volunteers in initiating and influencing the structure and development of hospices is not well recognised.
- Hospices are dependent on volunteers for support with awareness raising, fundraising and the delivery of services to patients.
- Whilst hospices are governed by trustees who are volunteers, there are still barriers to the tasks undertaken by volunteers within these same organisations, especially in children's hospices.
- Hospice volunteers do not always perceive that they are well managed.
- There are many more volunteers than paid staff in independent hospices and their contribution is not always well recognised or valued.

- Volunteers bring a different dimension of support to patients and families, mitigating the increasingly medicalised model of care.
- There is little knowledge of the link between volunteering and hospice sustainability.

It is clear that recent developments in palliative care policy have taken little account of the role which volunteers play within the UK independent hospice movement. This is perhaps unsurprising considering that the focus of these policies was on widening access to palliative care within the wider healthcare sector. However, volunteers are widely involved throughout the health and social care sector and the government are encouraging greater community involvement in these areas. These policy developments will undoubtedly influence the role and development of hospices. There are expectations of hospices in widening access to their services and in supporting the development of training of professionals in other settings. Set within an ageing population, where the incidence of those requiring hospice care is set to rise, along with a financial climate where funding is scarce, this is likely to mean that hospices will require significantly more support from volunteers. They will need additional voluntary support for fundraising and for patients and families as they seek to care for increasing numbers of people at end of life. However, the literature suggests that the incidence of people volunteering is fluctuating. A changing society also influences how and if people decide to donate their time and volunteer expectations are changing. Findings from the literature review indicate that current hospice volunteer management structures may not be conducive to the needs of today's volunteer. This, coupled with increasing

competition for volunteers, suggests that the current reliance of hospices on volunteering in its present form may not be sustainable. This should be of concern to hospices.

Therefore, drawn from professional experience and gaps in the literature, and drawing upon Fisher et al.'s (2003) organisational stages of development, my hypothesis is that volunteers have significant impact on organisational sustainability, influencing areas as diverse as governance, skill mix, service delivery, funding, organisational economy, accessibility and public education. This is also subject to external influences from society and government. A visual representation of this theory is depicted in Figure 1.1. This model in not intended to describe the reality of voluntary organisations but is more an aid for learning more about the relationships between, and effect of, external and volunteering influences on key organisational sustainability factors. The idea for the format of the diagram came from Cresswell (2003, p.124) "A Visual Model of Faculty Scholarly Performance". My theoretical model shows the elements of Organisational Sustainability in the central column and the External Influences on these in the left hand column with the relationship between these indicated by connecting arrows. The third column relates to Volunteering Influences and again connecting arrows demonstrate the relationships between External Influences and volunteering and the impacts that Volunteering Influences and Organisational Sustainability have on each other.

I will now go on to explain my hypothesis and the steps which I took in developing this.

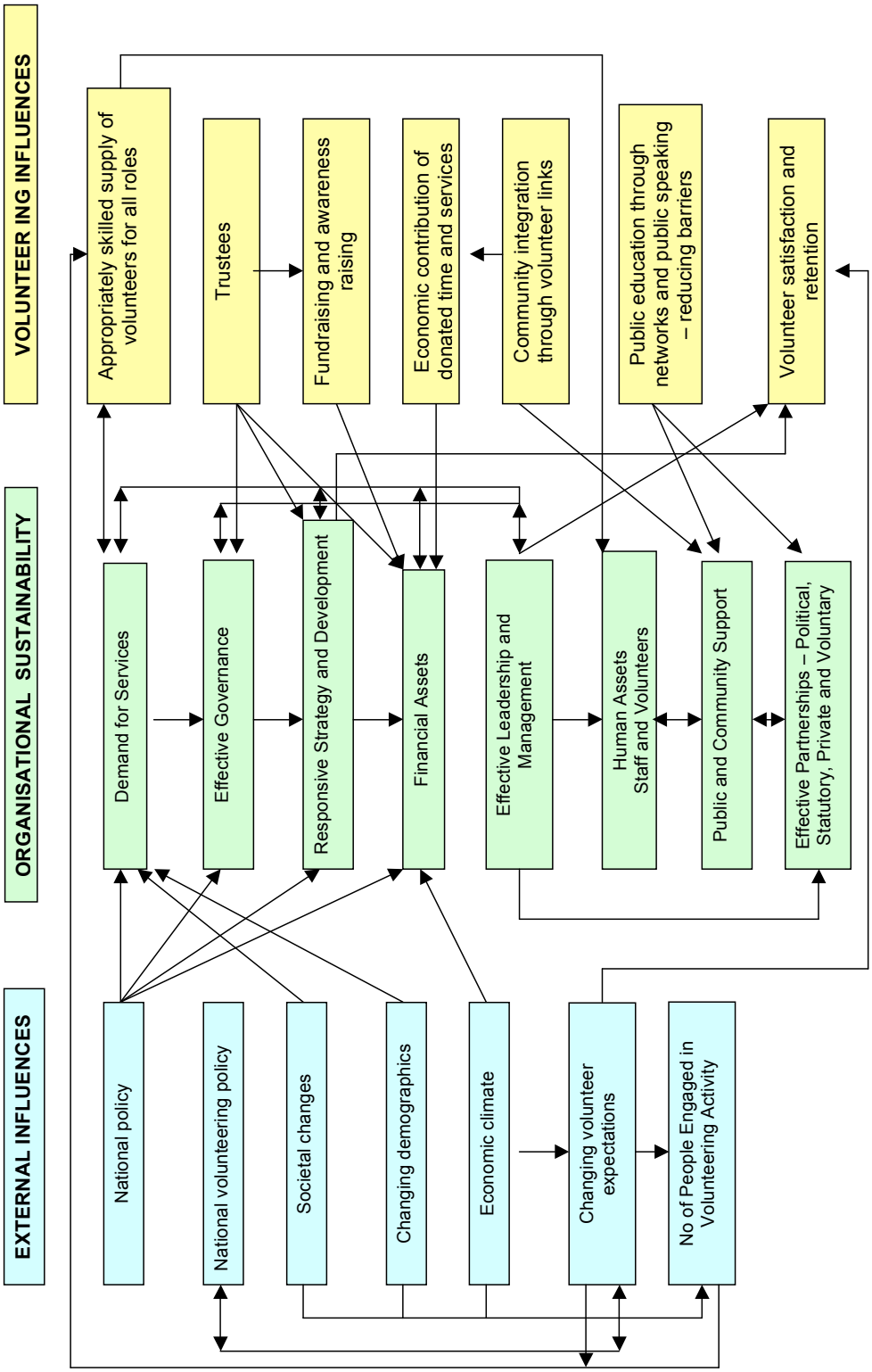

Figure 1.1: Diagrammatic representation of Theoretical Model of Volunteer Contribution to Voluntary Organisation Sustainability

1.5.2 Developing the theory

According to Kilduff (2006) on developing theory "the route to good theory leads not through gaps in the literature but through an engagement with problems in the world that you find personally interesting" (p252). I would suggest that the development of theory requires both of these elements. In constructing my own theory from the findings of the literature review, I applied Dubin's (1978) key stages of theory development. These are outlined in Table 1.9.

Table 1.9: Developing my theory using Dubin's key stages

Dubin's Stages	My Stages
Identify the particular area or unit	Identifying the area as volunteering in third sector organisations in UK.
Describe the effects that these have on each other	Describe the context of voluntary organisations and the external and internal influences on organisations and volunteering. Consider the effect of volunteering on organisations.
Describe the limits within which the theory may apply	My theory may apply within voluntary organisations, particularly those with a service delivery focus.
Describe how these units interact with each other	Describe the role of volunteers in the development of voluntary organisations. Demonstrate how external influences such as changing policy, society and economic factors influence organisational existence and the supply and retention of volunteers. Consider the impact of volunteers on organisations and how organisational approaches influence volunteering.
Develop conclusions	Volunteers have significant impact on organisational sustainability.

As part of my development of theory on volunteering and organisational sustainability, I first had to consider the factors, which influence ability of organisations to maintain and develop services. Based on my professional

experience, it is my view that there are a number of contributory influences which include eight key sustainability factors:

- continued demand for services;
- effective governance;
- responsive strategy and development;
- effective leadership and management;
- financial assets
- human assets: skilled staff and volunteers;
- public support;
- effective partnerships – political, statutory, private and voluntary sectors.

In relating this to hospices, external influences such as government policy, changing demographics, societal changes and economic climate affect not only the demand for services but also the ability of organisations to deliver these effectively. Volunteers also influence many of these sustainability factors through their contributions to governance and organisational direction as trustees; their addition to skill mix and experience of the staff team; their fundraising efforts and donation of time; enhancing care of patients and families; and making strong links with local communities generating public awareness, knowledge and support. All of this allows hospices to do so much more than would be possible without this voluntary resource. This voluntary resource, however, is also influenced by these same external factors and this can cause the supply of people wishing to give time to fluctuate, thus impacting on organisations so dependent on volunteers.

This paper is entitled " Strategic Asset or Optional Extra?" and I would suggest that based on the evidence from this literature review, that volunteering is indeed a strategic asset, contributing to the success and sustainability of hospice services. It is important that hospices understand the 'meaning' of this asset within their organisation and to be clear about the reasons for involving volunteers. Volunteering, like any other strategic asset, needs to be part of the organisational strategy, and effectively engaged, deployed and managed. To consider volunteering as an optional extra may threaten the ability of hospices to sustain services as currently structured, in the future.

1.5.3 Next steps: testing the theory

I discussed my theoretical model with three people, including the Chief Executive of a hospice, a voluntary sector consultant and a learning and development professional and refined this following their feedback. Looking at the applicability of the model in practice will form the basis for my research. Initially, this hypothesis is intended to apply to volunteer involving service delivery organisations of which hospices are one example. However, if testing with hospices supports this theoretical model, this may well support the need for further research to identify the applicability to other similarly structured voluntary organisations.

Chapter 2. Exploration of Theoretical Model in Practice - Methodology

2.1 Purpose of the Research

The purpose of this research was to test the applicability of my theoretical model in practice in both adult and children's hospices in the four countries of the UK by:

- exploring he influence of volunteers on four key organisational sustainability factors: governance, service delivery, hospice economy, and community engagement;
- gaining insight into how volunteering is understood by senior staff, volunteers and trustees in hospices;
- considering the relationship between volunteering and independent hospice sustainability in the UK.

Whilst the theoretical model shows eight organisational sustainability factors, findings from the literature review, in addition to my professional experience would suggest that the four key areas where volunteers have the most impact are governance, service delivery, hospice economy and community engagement. I chose, therefore, to explore these four factors from the theoretical model.

2.2 Research Question

Sarantakos (2005) states that the first step for the researcher is to identify and describe the topic to be researched. Creswell (2003) describes research

questions as falling into two distinct categories: " a central question and associated sub questions" (p105). He describes the central question as a broad outline of the focus of the research project. Denzin and Lincoln (2003) suggest that this will inform the subsequent methodology for the study.
My central research question, therefore, is: What is the relationship between volunteering and the future sustainability of UK independent hospices?"

2.3 Research Design

Crotty (1998) describes three key considerations when approaching the design of research studies:

- the paradigm behind the research design;
- the strategy which links the method to results;
- methods which will be used to gather and analyse data;

I have followed this approach in considering the framework for my study. My research fits within the Postpositivist paradigm. Cresswell (2003) describes Post positivism as challenging the Positivist view that truth is absolute, as it is not possible to be certain about knowledge claims when studying people.. Both quantitative and qualitative approaches would be used in Postpositivist research. In undertaking a study about volunteering in palliative care I was interested in exploring the relationship between volunteering and hospice sustainability. Volunteering in hospices is a complex phenomenon, experienced and understood differently by different people. I wished to test my Theoretical Model of Organisational Sustainability in the context of independent

hospices in the UK. My theory described eight key sustainability factors as outlined in Chapter 1, 1.5. 2 and suggested that volunteering has an impact on an organisation's ability to remain viable. I wanted to explore how volunteering was understood strategically by senior staff, trustees and also volunteers themselves.

There are, however, also elements of Pragmatism in my research. Cohen, Manion and Morrison (2011) describe Pragmatism as being driven by issues of practice and with a view to solving problems in practice. The subject of my research has been influenced by my own strategic and operational experience of managing volunteer services in hospices. Patton (1990) considers that in pragmatic knowledge claims, it is important that there is emphasis on understanding what works in practice and resolution of issues. My aim was to explore a wide range of opinions and suppositions, about how volunteers are perceived strategically by a range of practitioners, and how volunteering might influence hospice sustainability. Findings from this study, therefore, have the potential to identify issues and influence practice. In designing my data collection methods, I also took into account the audience for my research and have considered the best approach to provide the richest source of data possible to elicit findings, which might have resonance with most independent hospice settings.

I therefore used a survey method which is appropriate to a Postpositivist approach. This allowed me to approach the whole population of the UK independent hospices and to gather numerical data about the opinions of senior

staff, trustees and volunteers from as many respondents as possible. I included both quantitative and qualitative questions and tried to gather a wide range of views and opinions. The quantitative findings gave context to the qualitative data, and also helped to give an indication of the breadth and likely applicability of the outcomes from this research and my model.

2.4 Ethical Considerations

I applied for and received ethical approval from the University of Dundee Research Ethics Committee (UREC). As I did not involve patients or NHS professionals, I did not need NHS ethical approval through National Research Ethics Service (NRES). Additionally throughout the study, I worked at all times within the University of Dundee, School of Education, Social Work and Community Education Research Ethics Code of Practice. I informed all respondents that the study had received ethical approval from the University of Dundee Research Ethics Committee. I notified hospices informally to explore their interest and willingness to take part in the study. However, it was only once I received ethical permission from the University of Dundee, that I formally approached the hospices in the sample and invited them to take part in the study. Additionally, a number of hospices submitted my research proposal to their own hospice ethics committees before agreeing to take part in the study. All approved the research.

Foremost in my consideration of the ethical issues involved in this research, is the wellbeing of respondents. I clearly explained my reason for choosing this

topic, the focus of my research and my approach to data collection and analysis. This was achieved through a written explanation for everyone. People were also asked to give consent for taking part in the study by responding to the questionnaire. I also made clear to those taking part that they may decline to become involved and be assured that they had the right to withdraw from the research study at any time. The participant information sheet is attached as Appendix 3.

Respondents were also advised that their responses would be treated confidentially and that I would take the necessary steps to anonymise all information to reduce the possibility of identification. To assist with this, questionnaires had no names on the documentation and codes were used to refer to the role of the respondent and the hospice. I also gave information to everyone about the methods of storage, handling, and disposal of data both electronic and paper and assured them that all information would be handled in accordance with the Data Protection Act (1998).

One of the hospice organisations, which was included in the study, was my own organisation, Children's Hospice Association Scotland. I was concerned that my role as a senior manager within CHAS would inhibit some respondents from being completely open in their responses and might lead to the withholding of information. It was important, therefore, for me to clarify my role in the project and that my involvement was solely as a postgraduate student at the University of Dundee. I reminded respondents of the confidentiality undertaking, which I had given that all data collected, would be used only for the purpose of this

study. My research proposal was also scrutinised and approved by the CHAS Evaluation, Audit and Research group before I was permitted to proceed.

2.5 Scope of the study and sampling

I chose to involve only independent hospices within the UK and excluded any hospices which were funded by the NHS or other large UK charities such as Sue Ryder and Marie Curie. My reasons for this were that NHS hospices are fully funded by the NHS. Hospices run by Marie Curie and Sue Ryder are also fully funded by the national charity. This makes the organisational structure and resourcing of these hospices different to that of more local individual organisations and their inclusion might have skewed the findings from this study. Also, for my research to have impact and wide applicability, it needed to include a reasonable number of UK independent hospices.

Adult and children's hospices work differently, but both involve volunteers. I therefore felt it was important to involve both adult and children's hospices to give a broader understanding of the link between volunteering and sustainability. Additionally, I included adult hospices which also had a children's hospice as part of their organisation. I was keen that this study should explore similarities and differences between these different types of hospice organisations.

Sarantakos (2005) asserts that qualitative researchers use sampling approaches which are less rigid and structured than those used by quantitative

researchers. However, my study had a large quantitative component to give a context and extent to the qualitative findings. I, therefore, took a structured approach to sampling. As this study sought to understand volunteering from a strategic perspective, it was important that my sample included those responsible for the strategic direction of the hospice organisation, namely senior staff, including those with clinical roles (for example Chief Executive, Director of Finance, Director of Clinical Services, Medical Director) and trustees. It was also important to include volunteers in order to understand their views and experiences both in, and of, the strategic context. As previously discussed, the distinction between the terms 'trustee' and 'volunteer' is well understood in independent hospices these are defined in Chapter 1, 1.1.2. Hospice Boards where trustees serve and Senior Management Teams are generally not large and vary in size from hospice to hospice. For example a hospice senior management team can vary from approximately three to nine staff. Trustees may number between approximately 10-16. Volunteer numbers, however, can range from approximately 50 to 1000 or more. I therefore decided to sample three senior staff, three trustees and ten volunteers from each hospice, which whilst not statistically representative, did have some association with the relative size of each group.

I circulated my questionnaires to all independent hospices in the four countries of the UK which were members of Help the Hospices, 190 at the time of the study. However, a number of hospice organisations run more than one hospice but have one contact email address. Contact was therefore made only with the 181 'parent' organisations across Scotland, England, Northern Ireland and

Wales. I emailed each hospice giving them a brief outline of my study and inviting them to take part. I asked that they circulate the information for respondents (attached as Appendix 2) and relevant questionnaire links to three senior staff, three trustees and ten volunteers. The questionnaires are attached as Appendices 3-5. I had also planned to circulate the same information and an invitation to take part to the Voluntary Services Manager (VSM) in each hospice through their professional association: the Association of Voluntary Services Managers (AVSM). However, on reflection, I realised that this could result in confusion and duplication of effort, as because of the topic, hospices were likely to forward my enquiry to the VSM. I therefore decided not to involve AVSM.

I am aware in taking this approach that there was a three -fold risk. The first was risk of coercion from senior members of staff to trustees, staff and volunteers. This was, however, unlikely. The email was sent to the public email address for each hospice and this is likely to be accessed by administrative staff who do not hold a position of power within the hospice. It is unlikely that a senior member of staff would be in a position to exert influence over a trustee who technically line manages them, or to try to pressure each other. The second risk was that hospices would not forward the questionnaires and the third that there was no way of knowing how the senior staff, trustees and volunteers were selected.

2.6 Data collection and analysis

I employed an electronic questionnaire using the Bristol Online Survey system. I decided to use this method to enable me to reach a wider population of UK

hospices and enable me to explore a range of issues identified by my theoretical model. A questionnaire also enabled me to collect numerical data alongside information which was also descriptive and explanatory. I constructed three questionnaires: one for senior staff, one for trustees and one for volunteers with some core questions common to all three. The questionnaires were broadly similar in the content of questions, but not identical. This was to ensure that respondents would be able to answer the questions set and maximise both the amount and quality of the data. The questionnaire included both multiple-choice and a small number of free text questions. I used the literature review and my Theoretical Model to design the questions focussing on the following five areas: trustees and governance, the contribution of volunteers to the hospice, the role of volunteers in public and community involvement, why hospices involved volunteers, and what more volunteers could do to support the service.

The majority of the questions used the Likert Scale format with five options for respondents: Strongly agree, Agree, Disagree, Strongly Disagree and Not applicable. Questionnaires were all piloted with senior staff, trustees and volunteers in my own and one other hospice in England. These were not part of my sample and data from the pilot was not included in the final analysis. The piloting was to ensure that the questions were easy to understand and to elicit good quality information. Feedback was then used to refine and develop the survey.

The questionnaire was opened initially for four weeks but was extended twice following requests from hospices which still wished the opportunity to take part but needed more time to enable them to do so. A reminder was sent after three weeks to hospices that had not responded.

The questionnaire was anonymous and it was intended that it should take respondents no longer than 20 minutes. The questionnaires contained a section enabling those who wish to take part in interviews to give both consent and contact information. This information was noted separately to the questionnaire and deleted before the analysis of questionnaire data to ensure anonymity. Paper copies of the questionnaire were made available on request. Initially, I had intended to follow up the questionnaire with interviews, but the number of responses received generated significant breadth and depth of data and I concluded that the interviews would not be necessary.

Data from the Bristol Online Survey was analysed in a number of ways. Initially the quantitative information for each group of respondents was analysed using the systems available within the Bristol Online Survey System. Information was then exported to a spreadsheet where comparisons were made between the three groups of respondents to identify similarities and differences. Qualitative data were coded and analysed thematically, again comparing responses across the different participant groups. Data were also compared against hospice type and size to identify any convergent and divergent themes.

The range of respondents from different backgrounds, namely trustee, staff and volunteer allowed me to follow Sarantakos' (2005) recommendation that researchers should consider the data from a number of perspectives in order to deepen understanding and knowledge. This led to source triangulation. I also used inter-rater reliability to assess the accuracy of the initial data analysis. I shared a transcript with senior member of staff and a volunteer to see if they agreed with my themes and analysis of the qualitative data. They were able to confirm that they did.

Data have subsequently been presented as a narrative report, which include tables and figures to help to illustrate and give context to the findings. Data gathered were stored securely both electronically with password protected electronic files and hard copies were stored in a locked filing cabinet. This meets the requirements of the Data Protection Act 1998.

2.7 Consideration of Risks and Challenges

The main risk to the success of the study was a lack of response from hospice trustees, staff and volunteers. In order to mitigate this risk, I publicised my study through hospice newsletters from Help the Hospices and the Scottish Partnership for Palliative Care. This ensured that trustees, staff and volunteer managers would have an opportunity to engage with the study. This did, in fact, result in a number of requests by telephone and email for further details of the research by a number of hospice professionals in advance of my mailing. Whilst I anticipated that hospice staff and volunteers might be happy to

participate in the study, I was concerned that it might be more difficult to gain access to and engagement from hospice trustees. However, this concern proved to be unfounded. I also sent a follow up email after three weeks thanking hospices for taking part and reminding others that there was still time to take part should they still wish to do so.

Chapter 3 Results

3.1 Demographics

The analysis of findings is written under three key headings: Findings from Senior Staff, Findings from Trustees and Findings from Volunteers. However, before looking at these three areas, the response rates will first be considered. The questionnaire was sent to 181 independent UK hospices in all four countries of the UK of which 32 took part. No hospices in Wales or Northern Ireland responded. Therefore, 32 hospices from a total of 167 hospices in Scotland and England took part, giving a response rate of 19%. Breaking this down further by country, nine out of 12 independent hospices in Scotland participated giving a response rate of 75% and 23 out of 155 independent hospices in England giving a response rate of 15%. When embarking on this research, I had little expectation of reaching a high response rate but was keen to reach a reasonably broad spread of hospices in the UK.

There may be a number of factors which influenced the response rate. The only route to reaching respondents was through hospices. I, therefore, had to rely on the interest of the particular hospice and their willingness to make the questionnaires available to respondents. Volunteering is not always a priority for hospices and therefore the focus of the study might have led to the organisation deciding not to engage. There were also three other research studies into volunteering running prior to mine and three hospices cited their involvement in these as a reason for declining to take part.

As previously discussed, each hospice was asked to circulate the appropriate questionnaire to three senior staff, three trustees and ten volunteers. With 32 participating hospices, there was a potential for 96, 96 and 320 responses from each of these groups respectively. The actual response rate from these groups was as follows, senior staff, 60.4% (n=58); trustees, 58.3% (n=56); and volunteers, 54% (n=173). In total, 287 completed questionnaires were received from hospices in Scotland and England. Hospices were spread throughout England as follows: London area (n=3), Midlands and East England (n=6), North of England (n=8), South of England (n=6). Due to the small number of hospices in Scotland it would be easy to identify individual hospices from any geographic breakdown, therefore, this information has not been presented. However, respondents were spread across Scotland with the largest cluster in the central belt, including the Glasgow area. As mentioned earlier, there were no respondents from the 12 hospices in Wales or the two in Northern Ireland.

Of the hospices that responded, 24 were adult hospices; one of which provided day care and home care only, five were children's hospices; and three hospices ran both adult and children's services. I asked respondents to give the number of beds in their hospice so that I could group hospices taking part by size. This is a generally accepted method for describing hospice size in this field. Numbers of staff and volunteers engaged by each participating organisation also helped to give additional context to the study and allowed me to explore any relationship between hospice size, number of staff and volunteers. These data are shown in Table 3.1. It must be noted that the number of staff shown in Table 3.1 are likely to include both full and part-time staff. Volunteer numbers

will include volunteers who give different amounts of time as all volunteers have different levels of commitment.

Table 3.1 Comparison of hospices by bed size, number of staff and volunteers

Code	No. of beds	No. of staff	No. of Volunteers	Hospice Type
16	0	100 to 150	400 to 600	Adult
18	05 to 10	050 to 100	100 to 200	Adult
6	05 to 10	050 to 100	100 to 200	Children
10	05 to 10	050 to 100	200 to 400	Adult
23	05 to 10	050 to 100	200 to 400	Children
19	05 to 10	100 to 150	200 to 400	Children
28	10 to 15	050 to 100	200 to 400	Adult
2	10 to 15	050 to 100	400 to 600	Both Adult/Children
4	10 to 15	100 to 150	600 to 800	Adult
7	10 to 15	100 to 150	600 to 800	Adult
5	10 to 15	100 to 150	800 to 1000	Adult
17	10 to 15	100 to 150	800 to 1000	Adult
29	10 to 15	100 to 150	100 to 200	Children
22	10 to 15	150 to 200	over 1000	Adult
30	10 to 15	200 to 400	800 to 1000	Adult
14	10 to 15	over 200	600 to 800	Adult
3	10 to 15	over 200	over 1000	Adult
24	10 to 15	over 200	over 1000	Both Adult/Children
13	15 to 20	100 to 150	400 to 600	Adult
20	15 to 20	100 to 150	800 to 1000	Adult
9	15 to 20	150 to 200	800 to 1000	Adult
27	15 to 20	150 to 200	800 to 1000	Adult
11	15 to 20	150 to 200	over 1000	Both Adult/Children
8	15 to 20	150 to 200	over 1000	Adult
21	15 to 20	150 to 200	over 1000	Adult
26	15 to 20	over 200	800 to 1000	Children
25	15 to 20	over 200	over 1000	Adult
12	20 to 30	100 to 150	200 to 400	Adult
31	20 to 30	over 200	800 to 1000	Adult
32	20 to 30	150-200	200 to 400	Adult
15	over 30	over 200	600 to 800	Adult
1	over 30	over 200	800 to 1000	Adult

These data were further analysed to explore any trends between the number of beds and number of staff, the number of beds and number of volunteers, and the number of staff and number of volunteers. These are shown in Figures 3.1-3.4. I plotted the median point of each range in graphs linking beds and staff, beds and volunteers and staff and volunteers, and then used the scatter plot tool and a line of best fit. The larger diamond shapes depicted on the graph indicate multiple plot points with the same value overlapping in the diagram. I was looking for clusters of points close to or on the best-fit line. Some slight variation to this might be expected because the median point of each group was used. There is a fairly linear relationship between the number of beds and the number of staff, less so between number of beds and volunteers and no discernible relationship between numbers of staff and volunteers

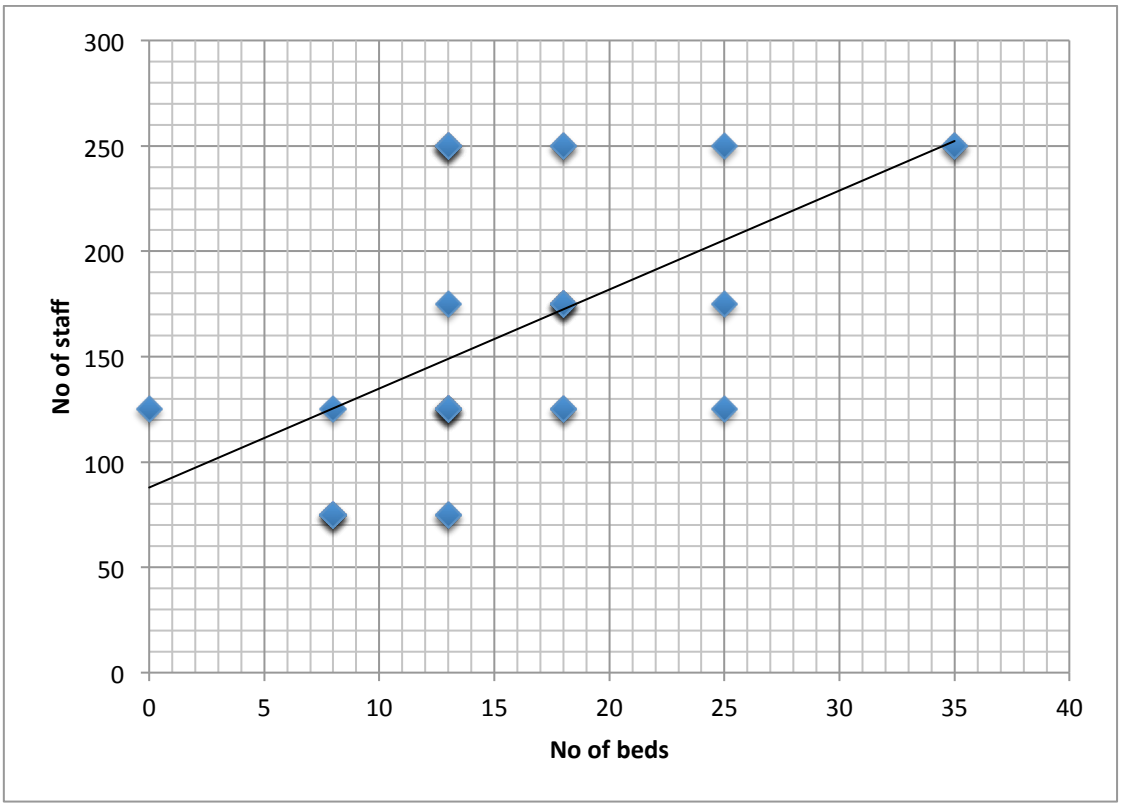

Figure 3.1 Trends between number of beds and number of staff – all hospices

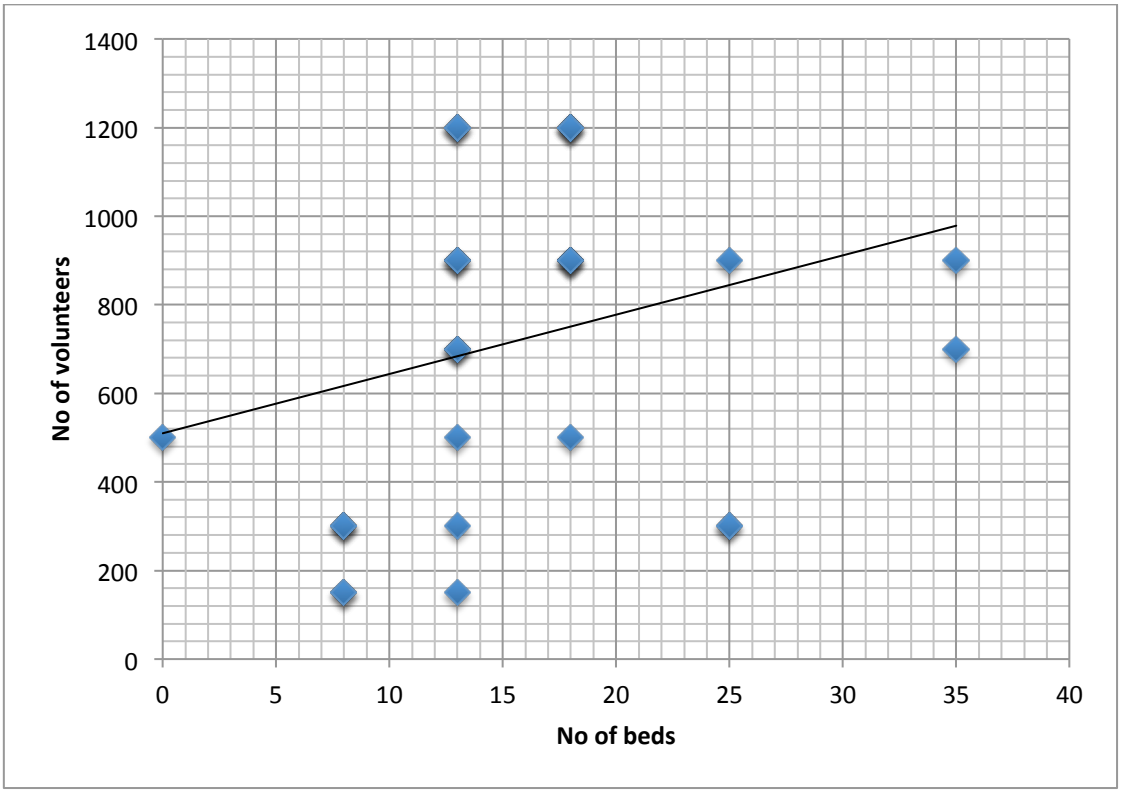

Figure 3.2 Trends between number of beds and numbers of volunteers – all hospices

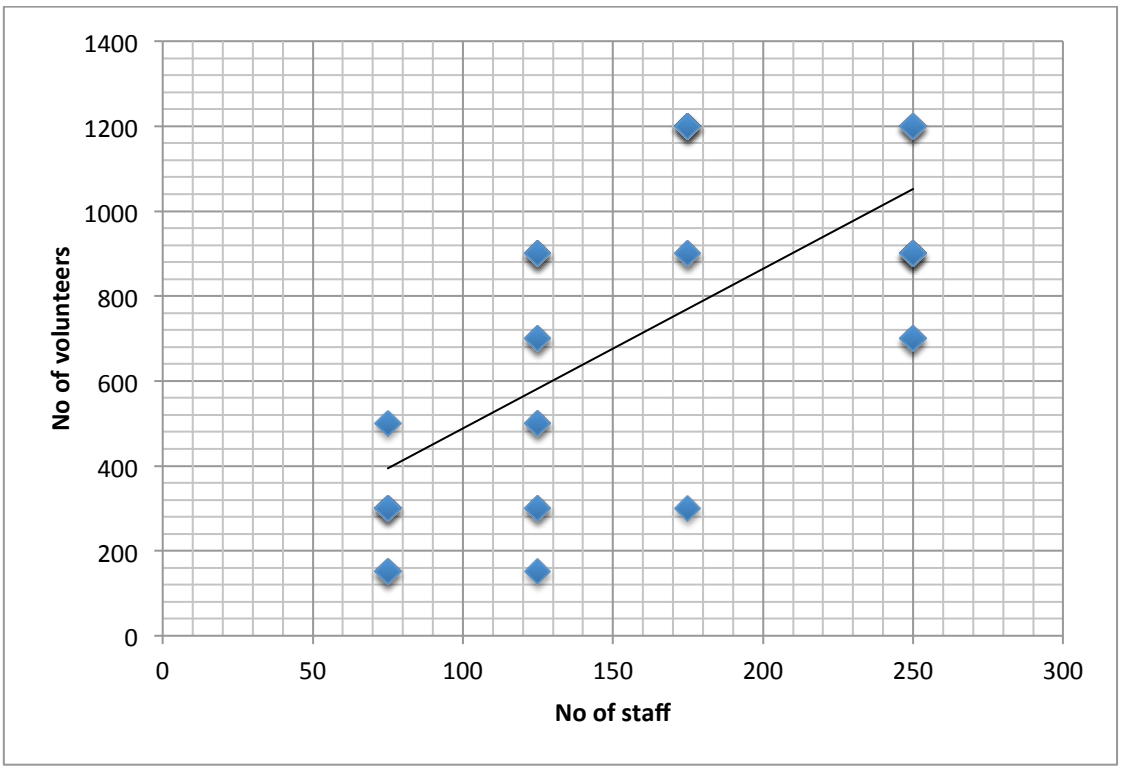

Figure 3.3 Trends between number of staff and number of volunteers – all hospices

This analysis was also undertaken to explore any similarities and differences between adult hospices, children's hospices and hospices providing both adults and children's services. It is interesting to note that in hospices which provided only children's services or both adult and children's services there is a slightly closer link between bed numbers and numbers of staff and also bed numbers and numbers of volunteers as shown in Figures 3.4 and 3.5. It is unclear why this should be. It appears from Table 3.1 that the larger children's hospices (over 10 beds) have fewer volunteers than adult services of a similar size. This may show less willingness to involve volunteers in some children's hospices when compared with their adult counterparts. However, the numbers participating in the study are very small and caution must be taken in interpreting these data. When comparing number of staff with numbers of volunteers as shown in Figure 3.6 the findings are very similar to the adult group and there are no obvious trends. This would tend to suggest an approach to the involvement of volunteers and development of voluntary services which is determined locally by each individual hospices.

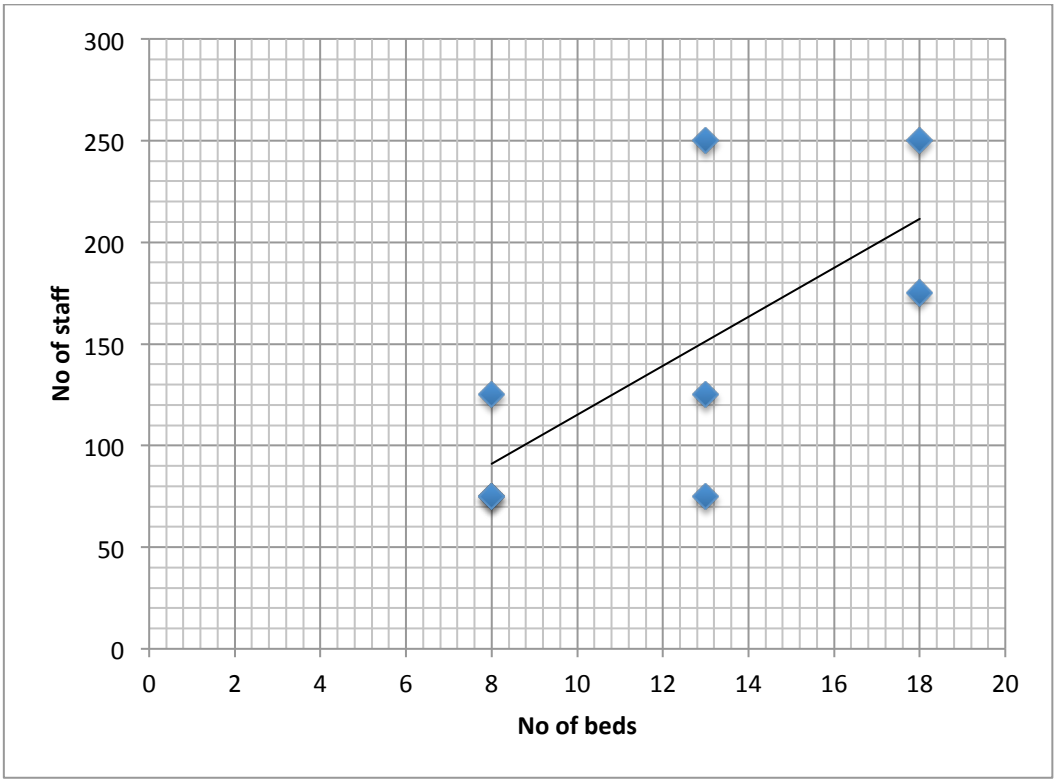

Figure 3.4 Trends between number of beds and number of staff – hospices providing a children's service

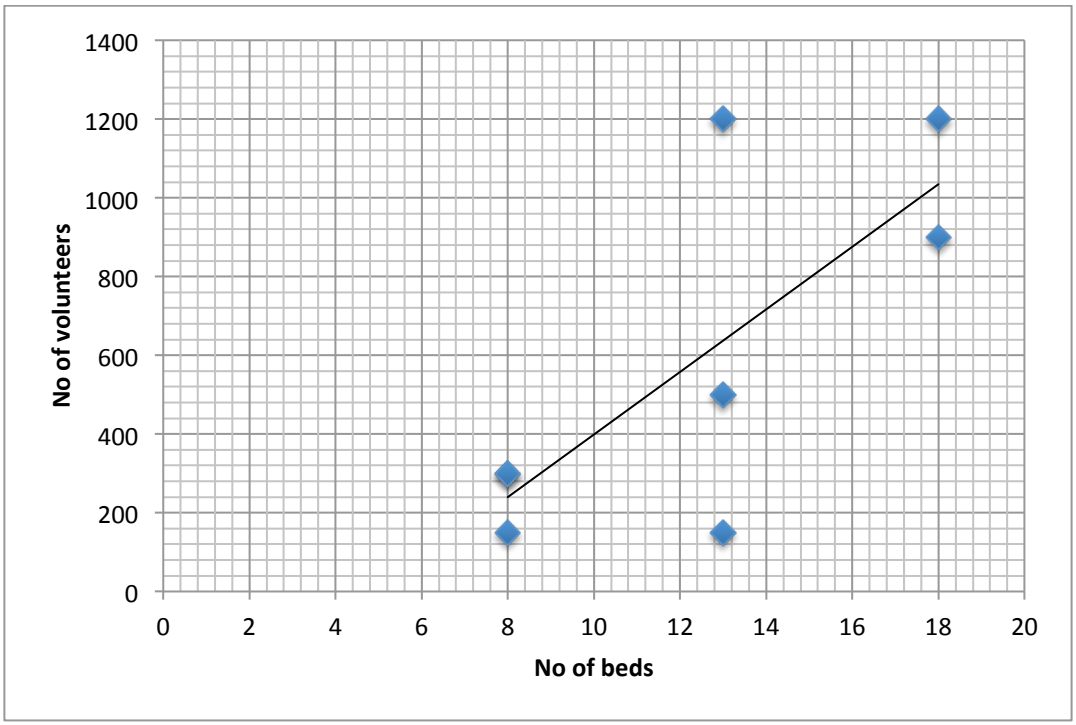

Figure 3.5 Trends between number of beds and numbers of volunteers – hospices providing a children's service

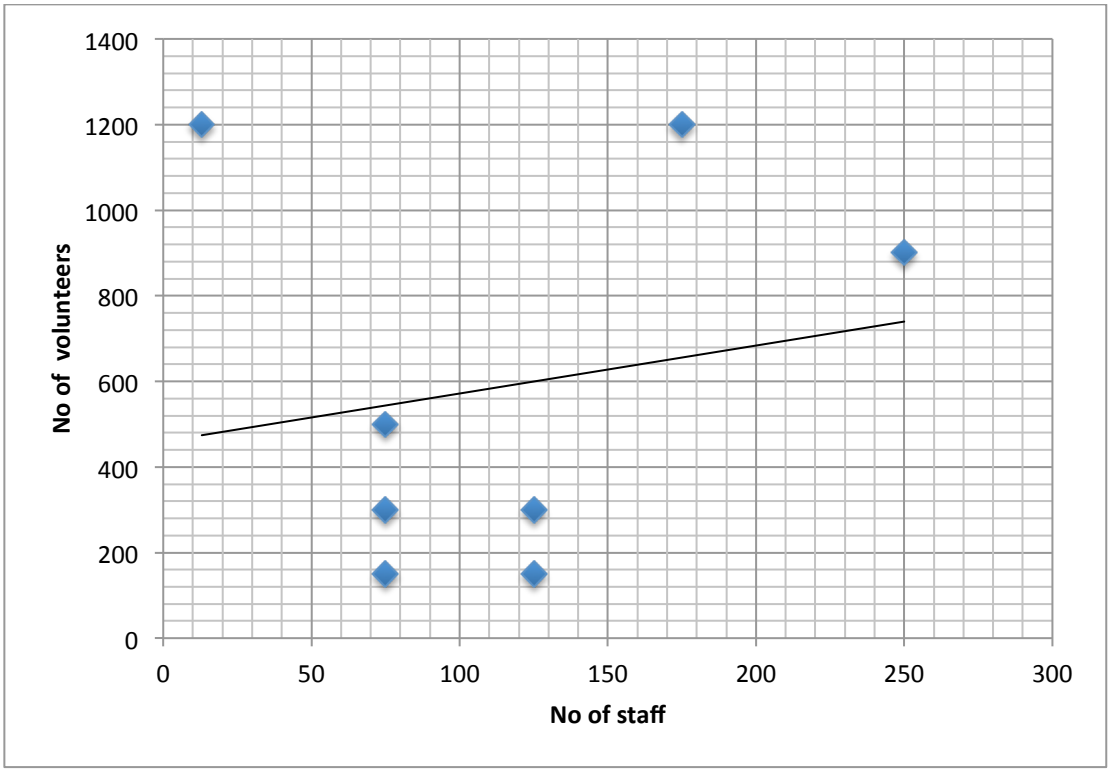

Figure 3.6 Trends between number of staff and number of volunteers – hospices providing a children's service

The study also considered how volunteers were managed. Findings indicate that in the majority of settings, volunteers are managed by a volunteer manager (VM) or volunteer co-ordinator (VC). There is no significant difference between adult hospices, children's hospices or those providing both of these services. A number of organisations have a shared management model where the VM or VC manages volunteers in conjunction with managers in other departments such as fundraising, retail and clinical. Only one hospice did not have a volunteer manager and, in this instance, volunteers were managed by the departments in which they worked. Two VMs were themselves volunteers. A breakdown of how volunteers are managed across hospices is shown in Table 3.2.

Table 3.2 Responsibility for Volunteer Management

Who Manages	No of Hospices	Adult	Children	Both
VM/VDM	17	12	2	3
VC	5	5	0	0
HR	1	1	0	0
VM/VC and others	6	4	2	0
Departments	1	0	1	0
No data	1	1	0	0

The questionnaires included Likert scale quantitative questions and a number of free text qualitative open questions. In reporting percentages for Likert scale responses, ‘strongly agree’ and ‘agree’, were combined and ‘strongly disagree’ and ‘disagree’ also amalgamated. This is because of the relatively small number of responses for each of these categories. The questionnaires were used to explore the following five areas: trustees and governance, the contribution of volunteers to the hospice, the role of volunteers in public and community involvement, why hospices involved volunteers, and what more volunteers could do to support the service. Not all questions were asked of all respondents. The reason for this was that it was possible that there were certain questions that some groups might not be in a position to answer. My purpose in taking this approach was to ensure that respondents did not abort the study if faced with difficult questions and to maximise the accuracy of information gathered. However, the core set of questions covered the same five areas as previously discussed. A summary of the comparison of findings across each group from the Likert scale questions is shown in Tables 3.4 to 3.6.

3.2 Findings From Senior Staff

There were 58 senior staff who responded to the study and they came from a variety of backgrounds including Chief Executives, Clinical Directors, Directors of Finance, Directors of Fundraising, HR Directors, Medical Director and Voluntary Services Managers. A breakdown of staff roles by number is outlined in Table 3.3. This was really helpful in giving a range of strategic views about volunteering from a senior level within hospices.

Table 3.3: Breakdown of respondent roles held by senior staff

Senior Staff	No
Chief Executives	12
Clinical Directors	11
Voluntary Services Managers	11
Fundraising/Marketing/Communication Directors	7
HR Directors/Manager	5
Clinical Managers	4
Finance Directors	3
Facilities and Support Director	1
Medical Director	1
Specialist Physiotherapist	1
Not identified	1

3.2.1 Senior Staff Responses-Trustees and Volunteering

Respondents were asked for their views on a range of questions relating to trustees, volunteering and strategy. Responses were broken down by hospice type and also by country, and are shown in Tables 3.4 and 3.7 respectively. As

the numbers are different for each group of respondents, percentages given should be considered with caution in all tables. A number of quotes are included in the following sections and the respondent codes given in the brackets relate to information given in Table 3.1.

As can be seen in Table 3.4 there was almost complete agreement from respondents in this group (95%) that staff recognised trustees as volunteers, however there was slightly less agreement (70%) as to whether they really understood the role of trustees. Senior staff in the main (79%) believed that trustees sought staff views but only 67% indicated that there were opportunities for staff to meet and talk with trustees. Almost all respondents (90%) strongly agreed or agreed that staff contributed to the organisation's strategic plan, whilst 46% strongly disagreed or disagreed that volunteers contributed to the plan. There was overwhelming agreement (90%) that volunteering was explicitly mentioned in the strategic plan with 73% indicating that the impact of volunteering was measured in their hospice.

There was strong agreement that hospices were explicit as to why volunteers were involved in the service with 97% of respondents strongly agreeing or agreeing. Almost all respondents saw volunteering as increasing the organisation's capacity to provide services with 98% of respondents strongly agreeing or agreeing. Indeed many respondents indicated that their hospice involved volunteers because they had a key role in supporting the delivery of services. *"Volunteers underpin and support the work of the hospice"* (senior staff, hospice 4).

Table 3.4 Analysis of findings from questionnaire section - Trustees and volunteering - by hospice type

Trustees and Volunteering	Staff % Strongly Agree/Agree				Trustees % Strongly Agree/Agree				Volunteers % Strongly Agree/Agree				
Hospice Type	All	Adults	Children	Both	All	Adults	Children	Both	All	Adults	Children	Both	N/S
Number of respondents	57	38	8	11	56	32	9	15	173	80	42	44	7
Staff understand trustees are volunteers	95%	92%	100%	100%									
Staff understand the role of trustees	70%	61%	88%	91%									
Volunteers in the organisation know that the trustees are volunteers					82%	78%	88%	87%	77% (157)	69% (68)	62% (39)	82%	(6)
Volunteers understand the role of trustees									74% (162)	65% (73)	67% (40)	75% (43)	(6)
Trustees seek the views of volunteers					84%	88%	50%	93%	55% (156)	88% (69)	40% (37)	57%	(6)
Trustees seek the views of staff	79% (56)	61% (37)	88%	91%	96% (55)	94% (31)	88%	100%					
Staff have opportunities to meet and talk with trustees	66%	58%	75%	91%	90%	91%	88%	93%					
Volunteers have opportunities to meet and talk with trustees					67% (55)	72% (31)	75%	47%	44% (158)	46% (70)	48% (39)	55% (43)	(6)
Staff contribute to strategic plan	90%	95%	75%	82%	98%	97%	100%	100%					
Volunteers contribute to strategic plan	34% (56)	53% (37)	50%	18%	52% (53)	50% 31)	50% (8)	53% (14)					
Volunteering is explicit in strategic plan	90%	92%	88%	82%	95% (55)	91% (31)	100%	93%					
Impact of volunteering in hospice is measured	73% (56)	74% (37)	50%	82%	82% (55)	75% (31)	88%	87%					
Volunteering increases ability of hospice to provide services	98%	100%	88%	100%	100%	100%	100%	100%	98% (171)	98% (79)	98% (42)	98%	(6)
The hospice states publicly why volunteers are involved	97%	95%	88%	100%	98%	100%	88%	100%	97% (167)	93% (76)	98%	96%	(5)

Numbers in brackets indicate that not all respondents answered this question and gives the actual number of those who did.

Code- respondents who strongly agree or agree with the statement		100% - 80%		79% - 60%		59% - 40%

Table 3.5 Analysis of questionnaire section – Volunteer contribution to hospice - by hospice type

Volunteer Contribution to Hospice	Staff % Strongly agree/agree				Trustees % Strongly agree/agree					Volunteers % Strongly agree/agree			
Hospice type	All	Adults	Children	Both	All	Adults	Children	Both	All	Adults	Children	Both	N/S
Number of respondents	57	38	8	11	56	32	9	15	173	80	42	44	7
Volunteers recognised as an integral part of the staff team	98%	100%	88%	100%	100%	100%	100%	100%	95%	94%	98%	93%	
There is a plan specifically relating to volunteering	74%	66%	88%	82%									
We know how many volunteers we need to deliver our service next year	75%	79%	50%	82%									
We consider how volunteers might contribute to new projects	91%	97%	50%	100%									
Volunteers bring skills which add to those of paid staff	98%	97%	100%	100%	100%	100%	100%	100%	97%	96%	100%	100%	
Volunteers bring a different approach to that of paid staff	100%	100%	100%	100%	91%	91%	75%	100%	87%	84%	90%	86%	
Volunteers are important to patient care	98%	100%	88%	100%	98%	100%	88%	100%	90%	96%	67%	95%	
Volunteers are important to the support given to families	97%	97%	88%	100%	96%	97%	88%	100%	87%	90%	81%	84%	
Volunteers contribute to the financial success of the hospice	100%	100%	100%	100%	98%	97%	100%	100%	99%	100%	95%	100%	
Volunteers help to make our services sustainable	98%	97%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	
Volunteers are important in raising funds	100%	100%	100%	100%	100%	100%	100%	100&	99%	99%	100%	100%	
There is a budget for volunteering	90%	92%	88%	82%									
The costs associated with volunteering are calculated	74%	65%	88%	91%									
The economic impact of volunteering is calculated	63%	58%	75%	73%	73%	72%	75%	73%					
The economic impact is used to inform future planning	53%	50%	50%	46%									
The hospice would not be able to provide all the services it does without volunteers	98%	97%	100%	100%	100%	100%	100%	100%	97% (170)	96% (78)	98% (41)	98%	

Numbers in brackets indicate that not all respondents answered this question and gives the actual number of those who did.

Code- respondents who strongly agree or agree with the statement		100% - 80%		79% - 60%		59% - 40%

Table 3.6 Analysis of questionnaire section - Public and community involvement – by hospice type

Public and Community Involvement	**Staff % Strongly agree/agree**				**Trustees % Strongly agree/agree**				**Volunteers % Strongly agree/agree**				
Hospice Type	All	Adult	Childre n	Both	All	Adult	Childre n	Both	All	Adult	Childre n	Both	N/S
Number of Respondents	57	38	8	11	56	32	9	15	173	80	42	44	7
Volunteers come from communities local to the hospice	100%	100%	100%	100%					86% (171)	86% (79)	83% (41)	82%	
Trustees come from communities local to the hospice					80%	97%	56%	93%					
Volunteers help to make the hospice part of the community	98%	97%	100%	100%	100%	100%	100%	100%	94% (171)	90% (78)	95%	95%	
Volunteers raise awareness in the community of the work of the hospice	100%	100%	100%	100%	100%	100%	100%	100%	99% (169)	99% (79)	93% (39)	98%	
Volunteers help to reduce the fear which surrounds hospices	91%	95%	75%	91%	96%	97%	100%	100%	90% (170)	88% (78)	86% (41)	91%	
Volunteers make it easier for people to use the services of the hospice	87%	89%	75%	91%	87%	91%	50%	100%	85% (169)	86% (79)	69% (39)	91%	
Volunteers help people in the community to talk about death and dying	64% (56)	61% (37	75%	64%	76%	84%	75%	87%	64% (167)	63% (77)	43% (40)	73% (43)	
Volunteers increase people's ability to support people in the community at end of life	73% (55)	68% (37)	75%	73% (10)	86%	81%	88%	93%	76% (167)	81% (77)	57% (39)	73%	
Volunteers bring the views of the community to the hospice	90%	87%	88%	100%	93%	91%	88%	100%	85% (170)	79% (79)	83% (40)	89%	
Volunteers have a lot to offer in helping the hospice to become more involved with the community	100% (55)	97% (37)	100%	91% (10)	100%	100%	100%	100%	93% (169)	90% (78)	67% (40)	95%	

Numbers in brackets indicate that not all respondents answered this question and gives the actual number of those who did.

Code- respondents who strongly agree or agree with the statement		100% - 80%		79% - 60%		59% - 40%

Table 3.7 Analysis of findings from questionnaire section - Trustees and volunteering - by country

Trustees and Volunteering	Staff % Strongly agree/Agree			Trustees % Strongly agree/Agree			Volunteers % Strongly agree/Agree		
Country	All	England	Scotland	All	England	Scotland	All	England	Scotland
Number of respondents	57	42	15	56	38	18	173	117	56
Staff understand trustees are volunteers	95%	93%	100%						
Staff understand the role of trustees	70%	74%	47%						
Volunteers in the organisation know that the trustees are volunteers				82%	84%	78%	77% (167)	91% (112)	55% (45)
Volunteers understand the role of trustees							74% (162)	85% (114)	60% (48)
Trustees seek the views of volunteers				84%	84%	89%	55% (156)	68% (110)	52% (46)
Trustees seek the views of staff	79% (56)	83% (41)	67%	96% (55)	95%	89%			
Staff have opportunities to meet and talk with trustees	66%	71%	53%	90%	89%	94%			
Volunteers have opportunities to meet and talk with trustees				67% (55)	74% (37)	56%	44% (158)	72% (110)	40% (48)
Staff contribute to strategic plan	90%	88%	93%	98%	97%	100%			
Volunteers contribute to strategic plan	54% (56)	50% (41)	73%	52% (53)	72% (36)	72% (17)			
Volunteering is explicit in strategic plan	90%	86%	100%	95% (55)	95% (37)	100%			
Impact of volunteering in hospice is measured	73% (56)	76% (41)	67%	82% (55)	82%	83%			
Volunteering increases ability of hospice to provide services	98%	98%	100%	100%	100%	100%	98% (171)	99% (114)	98% (55)
The hospice states publicly why volunteers are involved	97%	93%	100%	98%	97%	100%	97% (167)	99% (112)	98% (55)

Numbers in brackets indicate that not all respondents answered this question and gives the actual number of those who did

Code- respondents who strongly agree or agree with the statement		100% - 80%		79% - 60%		59% - 40%

Table 3.8. Analysis of questionnaire section – Volunteer contribution to hospice - by country

Volunteer Contribution to Hospice	Staff % Strongly agree/agree			Trustees % Strongly agree/agree			Volunteers % Strongly agree/agree		
Country	All	England	Scotland	All	England	Scotland	All	England	Scotland
Number of respondents	57	42	15	56	38	18	173	117	56
Volunteers recognised as an integral part of the staff team	98%	98%	100%	100%	100%	100%	95%	96%	96%
There is a plan specifically relating to volunteering	74%	71%	80%						
We know how many volunteers we need to deliver our service next year	75%	74%	80%						
We consider how volunteers might contribute to new projects	91%	93%	87%						
Volunteers bring skills which add to those of paid staff	98%	100%	93%	100%	100%	100%	97%	99%	98%
Volunteers bring a different approach to that of paid staff	100%	100%	100%	91%	92%	89%	87%	91%	86%
Volunteers are important to patient care	98%	98%	100%	98%	97%	100%	90%	97%	96%
Volunteers are important to the support given to families	97%	98%	93%	96%	95%	100%	87%	93%	98%
Volunteers contribute to the financial success of the hospice	100%	100%	100%	98%	100%	100%	99%	100%	100%
Volunteers help to make our services sustainable	98%	98%	100%	100%	100%	100%	100%	100%	100%
Volunteers are important in raising funds	100%	100%	100%	100%	100%	100%	99%	99%	98%
There is a budget for volunteering	90%	88%	93%						
The costs associated with volunteering are calculated	74%	79%	60%						
The economic impact of volunteering is calculated	63%	60%	73%	73%	66%	97%			
The economic impact is used to inform future planning	53%	53%	53%						
The hospice would not be able to provide all the services it does without volunteers	98%	98%	100%	100%	100%	100%	97% (170)	96%	96%

Numbers in brackets indicate that not all respondents answered this question and gives the actual number of those who did

Code- respondents who strongly agree or agree with the statement		100% - 80%		79% - 60%		59% - 40%

Table 3.9 Analysis of questionnaire section - Public and community involvement - by country

Public and Community Involvement	Staff % Strongly agree/agree			Trustees % Strongly agree/agree			Volunteers % Strongly agree/agree		
Country	All	England	Scotland	All	England	Scotland	All	England	Scotland
Number of Respondents	57	42	15	56		18	173	117	56
Volunteers come from communities local to the hospice	100%	100%	100%				86% (171)	86% (115)	90%
Trustees come from communities local to the hospice				80%	89%	89%			
Volunteers help to make the hospice part of the community	98%	98%	100%	100%	100%	100%	94% (171)	97% (115)	96%
Volunteers raise awareness in the community of the work of the hospice	100%	100%	100%	100%	100%	100%	99% (169)	100% (113)	98%
Volunteers help to reduce the fear which surrounds hospices	91%	93%	87%	96%	97%	100%	90% (170)	96% (114)	96%
Volunteers make it easier for people to use the services of the hospice	87%	93%	87%	87%	89%	97%	85% (169)	93% (113)	86%
Volunteers help people in the community to talk about death and dying	64% (56)	74%	53% (14)	76%	79%	83%	64% (167)	88% (111)	57%
Volunteers increase people's ability to support people in the community at end of life	73% (55)	79% (41)	67% (14)	86%	87%	97%	76% (167)	91% (111)	71%
Volunteers bring the views of the community to the hospice	90%	95%	73%	93%	89%	100%	85% (170)	93% (114)	82%
Volunteers have a lot to offer in helping the hospice to become more involved with the community	100% (55)	100%	100%	100%	100%	100%	93% (169)	98% (113)	88%

Numbers in brackets indicate that not all respondents answered this question and gives the actual number of those who did

Code- respondents who strongly agree or agree with the statement		100% - 80%		79% - 60%		59% - 40%

Respondents also commented that volunteers enhanced the range of care and services which the hospice was able to provide. Others added that volunteers increased the both the quality of care and level of support to patients and families. *"Volunteers put quality into the services we provide"* (senior staff, hospice 11).

When the responses from senior staff were broken down by hospice type across adult hospices (adult), children's hospices (children) and those organisations which had both an adult and children's hospice service (both) there was little difference between the responses for most questions. There were, however, five questions where there were marked differences. Fewer senior staff in adult hospices (61%) strongly agreed or agreed that staff understood the role of trustees (children- 88%, both 91%). A lower percentage of adult hospice staff strongly agreed or agreed (61%) that trustees seek the views of staff (children's hospices -88%, both 91%), or that they have opportunities to engage with trustees (adults 58%, children's 75%, both 91%). In children's hospices fewer senior staff strongly agreed or agreed (75%) that staff contribute to the strategic plan (adult hospices 95%, both 82%). A smaller number of children's hospices measured the impact of volunteering (50%) than adult hospices (74%, services providing both types of hospice (82%).

Findings were also broken down by country to identify the similarities and differences between Scotland and England. This was not broken down by hospice type as the numbers were very small and there is only one children's hospice organisation in Scotland which would have made it impossible to

maintain confidentiality and anonymity of the data. A lower percentage of senior staff in Scottish hospices strongly agreed or agreed (47%) that staff understand the role of trustees (England – 74%), that trustees sought their views (67%) (England 83%) or that staff had the opportunity to meet trustees (53%) (England 71%). However in English hospices, fewer senior staff strongly agreed or agreed (50%) that volunteers contribute to the strategic plan than their counterparts in Scotland (73%).

3.2.2 Senior Staff Responses - Volunteer contribution to the hospice

Views of respondents were sought on the contribution of volunteers to the hospice and a breakdown of responses by hospice type is shown in Table 3.5 and by country in 3.8. Only 2% of respondents strongly disagreed or disagreed that volunteers were viewed as an integral part of the team. "*We began and continue as a volunteer organisation – we just happen to employ over 200 people as well"* (senior staff, hospice 11). However, responses were more mixed as to whether there was a volunteering plan, with 62% in agreement. A significant percentage of senior staff (75%) believed that they knew how many volunteers would be needed to deliver the service the following year and 91% stated that they considered how volunteers might contribute to new projects. There was complete consensus (100%) that volunteers brought a different approach to that of paid staff with 98% of senior staff also of the opinion that volunteer skills added to those of paid staff. *"Volunteers bring breadth and depth to the organisation, enhancing the work of the professional staff"* (senior staff, hospice 3). *"Volunteers bring a diversity of skills, experience, energy and*

can offer a different perspective on ideas and day to day practice" (senior staff, hospice 22). *"They provide extra resource, skills and expertise"* (senior staff, hospice 2). Only 2% strongly disagreed or disagreed that volunteers were important to patient care whilst 3% strongly disagreed or disagreed that volunteers were important to the support given to families. Some respondents also highlighted that volunteers maintained the culture of the organisation and enhanced the work of the organisation. *"Volunteers bring added value to our work"* (senior staff, hospice 26).

Respondents also indicated that the reason their hospice involved volunteers was that they brought additional skills, knowledge and diversity, multiplying and enriching that of the staff team. Many respondents commented that the new and additional skills contributed by volunteers allowed the hospice to provide additional services. The involvement of volunteers according to some respondents added to the diversity of the staff team and the holistic nature of the care provided.

There was complete agreement (100%) that volunteers contributed to the financial success of the hospice and that volunteers were important in raising funds. The majority of senior staff (98%) believed that volunteers helped to make their hospice service sustainable. *"Volunteers make services sustainable and make the overall patient experience less clinical"* (senior staff, hospice 12). The questionnaire then explored budgets and costs associated with volunteering. The majority of respondents (89%) indicated that their hospice had a budget for volunteering, whilst only 74% strongly agreed or agreed that

the costs associated with volunteering were calculated. This seems to be somewhat contradictory, as it might seem that costs associated with volunteering would need to be calculated in order to budget effectively. It appeared that fewer hospices calculated the economic impact of volunteering with only 63% agreeing that this was the case. Just over half of respondents in this group (53%) believed that the economic impact of volunteering was used to inform future planning. Respondents overwhelmingly strongly agreed or agreed (98% - 83% strongly) that the hospice would not be able to provide the service it does without volunteers.

When senior staff were asked to give the reasons that their hospice involved volunteers, whilst a small number of respondents referred to the role of volunteers in fundraising, by far the majority of comments related to cost saving, enabling services to be cost effective and permitting more services to be delivered. "*They enable the hospice to deliver services which it could not afford to fund without them"* (senior staff, hospice 22). Five respondents stated that their hospices would not exist, or be in a position to operate effectively without the involvement of volunteers. *"(Name) hospice would not exist without our extensive team of volunteers"* (senior staff, hospice 20). "*Without them we would not be able to deliver our services"* (senior staff, hospice 6). One participant stated that their reason for involving volunteers was *" to make our services sustainable"* (senior staff, hospice 12).

Whilst there were strong similarities in responses for the majority of questions, once again when these were broken down by hospice type there were five

areas of difference. Fewer senior staff in adult hospices strongly agreed or agreed (66%) that there was a plan in place for volunteering (children 88%, both 82%). A lower percentage of children's hospices (50%) knew how many volunteers they needed to deliver future services (adults 79%, both 82%). Fewer senior staff from children's hospices strongly agreed or agreed (50%) that they knew how many volunteers are needed to deliver the service in the next year, than their counterparts in other hospice types (adults 97%, both 100%). A lower number of adult hospices strongly agreed or agreed (65%) that the costs associated with volunteering were calculated (children 88%, both 91%). When responses were again broken down by country, there was little difference between Scotland and England across almost all questions.

3.2.3 Senior Staff Responses - Public and community involvement

The role of volunteers in public and community involvement was then explored and a breakdown of responses to this section is shown by hospice type in Table 3.6 and by country in Table 3.9. There was absolute agreement that volunteers came from communities local to the hospice (100%), that they helped to make the hospice part of that community (98%) and that volunteers raised awareness of the work of the hospice in communities (100%). *I believe volunteers are the true owners of the hospice"* (senior staff, hospice 19). *" The hospice belongs to the community and volunteers are a very important part of this"* (senior staff, hospice 24). There was largely consensus as to whether volunteers helped to reduce the fear which surrounds hospices (91%) but views were more mixed about volunteers making it easier for people to use the services of the hospice

(87%) and helping the community to talk about death and dying (64%). Over a quarter of respondents (26%) strongly disagreed or disagreed that volunteers increased people's ability to support people in the community at end of life. However, 89% of senior staff strongly agreed or agreed that volunteers brought the views of the community into the hospice and 100% responded that volunteers have a lot to offer in helping the hospice to become more involved with the community. *"They create opportunities for the local community to be part of a valued resource"* (senior staff, hospice 17). Many respondents commented that a key driver for the involvement of volunteers was community involvement. *"Volunteers provide a voice and presence for the hospice in the local community"* (senior staff, hospice 20). Volunteers also enabled *"community engagement and changing attitudes"* to hospices (senior staff, hospice1). A small number of respondents also spoke of the ambassador role which volunteers have, their involvement in raising awareness and contribution to public relations.

When findings were analysed across hospice type, there was more agreement in the findings than in the previous two sections. There were fewer responses from senior staff in children's hospices that indicated that they strongly agreed or agreed (75%) that volunteers helped to reduce the fear that surrounds hospices than from their counterparts in the other sectors (adult 95%), both 91%), or that volunteers made It easier for people to use the hospice (75%) (adult 89%, both 91%).

In comparing responses from senior staff in Scotland and England there were only three questions where perceptions differed. Fewer senior staff in Scotland strongly agreed or agreed (53%) that volunteers helped people in the community to talk about death and dying (England 74%), or that volunteers increased community capacity to support people at the end of life (67%) (England 79%). Once again, a lower number of staff in Scotland strongly agreed or agreed (73%) that volunteers bring the views of the community into the hospice (England 95%).

3.2.4 Senior Staff Responses – Further roles for volunteers

A further free text question explored senior staff views about what else volunteers could do to support the hospice. There were fewer responses to this question with only 24 out of a possible 57. Eleven of those who did respond indicated that they were keen to see volunteers become more involved in patient care. Areas suggested included; basic nursing care, family support, counselling, chaplaincy and befriending patients both in the hospice and community. Five respondents believed that what their hospice needed was "more of the same" and that they felt that there was nothing more that was needed in terms of volunteer contribution. Other suggestions included volunteers raising awareness of the hospices services, supporting the hospice with community engagement, reaching out to ethnic communities, supporting the development of services, helping the understanding of what hospices do. *"Volunteers help to dispel myths and taboos about the hospice, and death and dying in general"* (senior staff, hospice 13). There was clear commitment from a

number of respondents to being open to seeing volunteer roles develop into new areas. *"I would like to see volunteers in every area of our work"* (senior staff, hospice 19). "*We would consider anything and everything to support services and enhance them and also when looking at the workforce to sustain services"* (senior staff, hospice 15). "*We constantly push the boundaries on this as we discover the talents and interests of individual volunteers"* (senior staff, hospice 12).

3.2.5 Summary of findings from senior staff

There was broad agreement in the findings from senior staff across all hospice types that would suggest that volunteers are highly valued, and seen as an integral part of the professional team. Findings from this group suggest that volunteers add to the quality of care and the skill mix of the staff team, bringing skills, experience and diversity. There was evidence to suggest that the range of services offered by the hospice is dependent on the volunteering contribution. Senior staff view volunteers as making a significant economic impact and that the sustainability of the hospice is dependent on the volunteering component of the organisation. The questions about trustees revealed greatest divergence of views across hospice types and also countries. Senior staff, however, recognise the need for and appear to be committed to new roles for volunteers in the future, especially in patient care and overwhelmingly identify a significant dependence on volunteers for service delivery; care and support of patients; community engagement; and public education.

3.3 Findings From Trustees

A total of 56 trustees responded and just as with senior staff, they undertook a range of roles ranging from clinical, to finance and business. Again, this was valuable in giving a range of different perspectives on volunteering. A number of quotes are included in the following sections and the respondent codes given in the brackets relate to information given in Table 3.1. The roles held by respondents are shown in Table 3.10.

Table 3.10: Breakdown of respondent roles held by trustees

Trustee Roles	No
Clinical /Medical	11
Business/Trading	10
Finance/Audit/Investment	8
Chairperson	6
Generalist/Lay person	6
HR	4
Fundraising	3
Corporate Governance	2
Legal	2
Property	1
Volunteers	1
Not identified	2

3.3.1 Trustee Responses - Trustees and Volunteering

In this section of the questionnaire, respondents were again asked for their views on a range of areas relating to trustees, volunteers and strategy. A breakdown of responses in this section by hospice type and by country is shown in Tables 3.4 and 3.7 respectively. Once again percentages should be

considered with caution throughout, as the number of respondents was different in each group. Many respondents (82%) strongly agreed or agreed that volunteers did recognise that trustees were also volunteers. The majority of respondents (96%) indicated that trustees sought the views of staff, with a lower percentage (84%) in agreement that views of volunteers were pursued. However, in comparing responses from respondents regarding engagement with staff and volunteers, 90% of respondents believed that staff had the chance to meet and talk with trustees as opposed to only 67% considering that volunteers had the same opportunity.

There was almost complete consensus (98%) that staff contributed to the organisation's strategic plan. However, only 52% considered that volunteers were engaged in contributing to the process. A majority of trustees concurred (95%) that volunteering was explicitly mentioned in the strategic plan with 82% in agreement that the impact of volunteering was measured in their hospice. Respondents were unanimous (100%) that volunteering increased the organisation's ability to provide services. *" They add skills, time, experience and breadth of views that we could not afford to pay for and which the hospice would be poorer without"* (trustee, hospice 22). "*To employ staff to provide the services carried out by volunteers would be cost prohibitive"* (trustee, hospice 12). There was also strong agreement that the hospice was explicit as to why volunteers were involved in the service (98%).

In looking at the data across hospice type there were four main areas of difference in the responses from trustees. Fewer trustees in adult hospices

strongly agreed or agreed (78%) (children 88%, both 87%) that volunteers knew that the trustees were volunteers or that the impact of volunteering was measured (75%) (children 88%, both 87%). A lower percentage of children's hospice trustees strongly agreed or agreed (50%) that trustees seek the views of volunteers (adult 88%, both 93%). Fewer trustees from hospices that provided both adult and children's hospice services strongly agreed or agreed (47%) that volunteers had opportunities to meet trustees (adult 72%, children 75%).

When findings were again broken down by country, a lower number of trustees in Scottish hospices strongly agreed or agreed (78%) that staff understand the role of trustees (England 84%), or that staff contribute to the strategic plan (56%) (England 74%).

3.3.2 Trustee Responses - Volunteer contribution to the hospice

Trustees were asked for their opinions on the contribution which volunteering makes to the hospice. A breakdown of these responses by hospice type is shown in Table 3.5 and by country in Table 3.8. There was complete agreement (100%) that volunteers were seen as an integral part of the team and that volunteers brought skills which enhanced those of paid staff. Volunteers were variously described as "supporting", "enhancing" and "adding value" to hospice services. *"Volunteers are an essential part of the quality of care provided by the hospice"* (trustee, hospice 21). *"They are a close and integral part of the running of the hospice"* (trustee, hospice 16). *"We involve volunteers to access skills*

that may benefit the hospice" (trustee, hospice 6). *"The hospice can utilise the disparate skills that they can bring to add to the services that the hospice brings to the community"* (trustee, hospice 10). The majority of trustees (91%) believed that volunteers had a different approach to that of paid staff with 98% indicating that volunteers were important to patient care. Again a large number of respondents (96%) concurred that volunteers were important to the support given to families.

Trustees also indicated the importance of volunteers as ambassadors, the recognition that volunteers had founded the hospice and the role of volunteers in delivering strategy. One respondent, however, highlighted that whilst volunteers added value in many ways but there were also challenges. *"They do have the effect of increasing the complexity of staff workloads"* (trustee, hospice 1).

Turning to the economic impact of volunteering 98% of respondents in this group were of the opinion that volunteering was key to the financial success of the hospice, and 24% disagreed that the economic impact of volunteers was calculated. Overwhelmingly respondents indicated (100%) that volunteers made the hospice sustainable, that volunteers were important in raising funds and that without volunteers the hospice would not be able to provide the services that it did. *"The financial rewards are enormous: for fundraising, absolutely essential"* (trustee, hospice 4). There were nine responses which stated that the hospice was dependent on volunteers for survival: *"to survive day to day"* (trustee, hospice 16). *"Because they are invaluable and we would*

fold without them" (trustee, hospice 23). *"We would have to close the hospice if we didn't have the support of our volunteers"* (trustee, hospice 15).

There was broad consensus on all questions from trustees across all hospice types and only one main area of difference when broken down by country. More trustees from hospices in Scotland agreed or agreed (97%) that the economic value of volunteering is calculated than their counterparts in England (66%).

3.3.3 Trustees Responses - Public and community involvement

Opinions about volunteering and community involvement were also explored with trustees. Responses, broken down by hospice type are shown in Table 3.6 and by country in 3.9. A significant number of respondents (89%) strongly agreed or agreed that they as trustees came from communities local to the hospice. Trustees also perceived that volunteers helped to make the hospice part of that community (100%) and that volunteers raised awareness of the work of the hospice locally (100%). "*Volunteers add significant value to the services we provide in all ways, and act as strong links to our local community"* (trustee, hospice 1). There was a high level of agreement that volunteers help to reduce the fear which surrounds hospices (96%) but respondents were less strongly convinced about volunteers making it easier for people to use the services of the hospice (87%) and helping the community to talk about death and dying (76%). A high number of trustees (86%) concurred that volunteers increased people's ability to support people in society at end of life, and with

93% of the opinion that volunteers brought the views of the community into the hospice. Respondents overwhelmingly (100%) perceived that volunteers had a lot to offer in supporting the hospice with becoming more engaged with the community. Community engagement was seen as an important reason for the involvement of volunteers. Several trustees highlighted the importance of a strong community presence and links with the community in which the hospice was located. They clearly saw volunteering as a way to do this. *"The hospice is for the community, by the community and people want to be involved and help"* (trustee, hospice 10). *"The hospice is an integral part of the community it serves and the involvement of volunteers is essential to the vision and culture of the organisation we seek to maintain"* (trustee, hospice 27).

Again there was close agreement amongst all questions in this section when broken down by hospice type with the exception of two questions. A lower percentage of trustees from children's hospices strongly agreed or agreed (50%) that they came from communities local to the hospice (adult 84%, both 87%) or that volunteers help people in the community to talk about death and dying (75%) (adult 84%, both 87%). There was little difference in responses between trustees in English and Scottish hospices.

3.3.4 Trustee Responses - Further roles for volunteers

Trustees were asked what more volunteers could do to support the hospice and only 29 from the total number of respondents (56) made any suggestions. Responses indicated that trustees were very happy with the contribution which

volunteers made. *"We have an excellent record of steady growth in volunteers who are celebrated, supported and valued and take advantage to help in all areas"* (trustee, hospice 16) and *"Volunteers have a fantastic attitude - they are enthusiastic, positive and energetic. They can do as much or as little as they wish. Their attitude and commitment adds to the positive ethos of x hospice"* (trustee, hospice 26).

Almost half of the respondents indicated that all that was required was "more of the same". Six trustees highlighted the need for additional ambassador roles to raise the profile and understanding of the hospice. One suggested that volunteers could be a resource to schools in terms of fundraising and supporting aspects of the curriculum which relate to death and dying. Another participant suggested that volunteers had a greater role to play in "compassionate communities": projects which aim to develop and support the capacity of local people to support those at end of life and to reduce the 'taboos' which surround death and dying. Four respondents suggested that volunteers could have a larger role in care whilst six indicated that they were undertaking a review to identify new areas for volunteering. *"We continue to examine where, with training, volunteers can be used rather than paid staff"* (trustee, hospice 22).

3.3.5 Summary of findings from trustees

Findings from trustees also indicate that volunteering is greatly valued. However trustees overall perceive that they engage well with senior staff and volunteers but this is not supported by the views of these respondents. There

are different trustee perceptions about these areas across all hospice types and between England and Scotland. Trustees also recognise volunteers as an integral part of the hospice team and being important to the care of patients and families. Trustees also seem to be committed to new roles for volunteers in the future, especially in community engagement, but also in patient care. The views of trustees support those of senior staff in strongly identifying a significant reliance on volunteers for service delivery, care and support of patients, community engagement and public education. However, this group place more emphasis on cost-effectiveness, service delivery and community engagement. Trustees also view volunteers as having a considerable economic impact recognising also that the hospice relies heavily on this resource for sustainability and in a small number of instances, continued existence. Findings from this group also show evidence of a commitment to exploring new ways for volunteers to become involved in the future, with a focus on patient care, raising awareness and public education.

3.4 Findings From Volunteers

Respondents from this group held a wide variety of volunteering roles, with these being grouped into 26 categories. There was also evidence of volunteers who had more than one role. Of the 173 responses, 130 volunteers gave only one role, whilst 31 had two, 10 had three and two volunteers had four different roles. Some volunteers gave only “patient volunteer” or “ward volunteer” so it is unclear as to how many had hands on care roles beyond those who were specific about this. A breakdown of all the volunteer roles by frequency of response is shown in Table 3.11.

Table 3.11: Breakdown of respondent roles held by volunteers

Volunteer Roles	No
Reception	43
Driver	26
Fundraising	21
Administration/Secretary	17
Working with patients/ward roles (including children)	16
Day Care	15
Hospice café/coffee shop	10
Retail	12
Hospice Kitchen/Catering	9
Ambassador	6
Complementary Therapy	5
Estates/Gardens/Head Gardener	5
Bereavement support	4
Finance	3
General roles not specified	3
Housekeeping/laundry	3
HR	3
Befriending	2
Patient database -Crosscare/ IT	2
Voluntary Services Manager	2
Choir	1
Counsellor	1
Patron	1
Research and development	1
Team Leader	1
Volunteer Transport administration	1

3.4.1 Volunteer Responses - Trustees and Volunteering

A breakdown of responses by hospice type is shown in Table 3.4 and by country in Table 3.7. There was also a free text questions relating to the reasons why their hospices involved volunteers. A number of quotes are

included in the following sections and the codes given in the brackets relate to information given in Table 3.1. Percentages should be treated with caution throughout as the numbers were different for each group of respondents. There was a high level of agreement (77%) about whether volunteers recognised trustees as volunteers. Again there was a range of views as to whether volunteers understood the role of trustees with 74% agreeing, only 55% indicating that trustees sought their views and only 44% highlighting that there were opportunities to meet and talk with trustees.

There was a strong consensus (98%) that volunteering increased the organisation's capacity to provide services. "*The hospice involves volunteers in so many ways, all of which contribute greatly to the services and facilities and facilities we are able to provide"* (volunteer, hospice 22). Respondents also commented that volunteers extended and "improved" the range of services and care which the hospice was able to provide). *"Without volunteers the hospice would neither be able to raise the funds necessary to sustain the service it provides, nor be able to afford the staff necessary to provide the level of service for the patients which the hospice expects to provide"* (volunteer, hospice 20). Volunteers also perceived that the hospice was explicit as to why volunteers were involved in the service (97%).

When volunteer responses are compared by hospice type there is broad agreement across all questions. There are two specific areas of difference. More volunteers from organisations which have both adult and children's hospices agreed or strongly agreed (82%) that volunteers know that trustees are also volunteers (adult 69%, children 67%). Additionally, a greater number of volunteers in adult hospices strongly agreed or agreed (88%) that trustees seek the views of volunteers (children 40%, both 57%).

There were also significant differences in the responses from volunteers in Scotland and England across a number of questions. A higher percentage of volunteers in England strongly agreed or agreed that volunteers know that trustees are volunteers (91%) (Scotland 56%) and that they understand their roles (85%) (Scotland 60%). There is also disparity between countries on perceptions of trustees seeking the views of volunteers (strongly agree or agree England 68%, Scotland 52%) and opportunities to engage with trustees (strongly agree or agree England 72%, Scotland 40%).

3.4.2 Volunteer responses - Volunteer contribution to the hospice

Volunteers were asked for their views on the volunteering contribution to the hospice in general, rather than on their particular contribution. A breakdown of responses to this section by hospice type can be seen in Table 3.5 and by country in Table 3.8. The majority (95%) strongly agreed or agreed that volunteers were recognised as an integral part of the team. Respondents were almost unanimous (97%) that volunteers brought skills which enhanced those of

paid staff, but only (87%) believed that they had a different approach to that of employees. Respondents were of the opinion that volunteers were important to patient care (90%) and also to the support given to families (87%). Volunteers were also asked to give reasons why their hospice involved volunteers and there was clear recognition of the role of volunteers in bringing additional and complementary skills and "life experiences" to those of paid staff. They highlighted that volunteers "*take pride in working in the hospice"* (volunteer, hospice 27). However, only in this group was a link made between volunteers and a *"personal service to patients*" (volunteer, hospice 9) or an *"important link between the hospice, patients and relatives"* (volunteer, hospice 11) or "normalising" the hospice experience.

There was almost complete agreement (99%) that volunteers contributed to the financial success of the hospice and that volunteers were important in raising funds and helped to make hospice services sustainable. Volunteers very clearly see themselves as helping to reduce running costs: *"to help keep costs down"* (volunteer, hospice 19) and *"to provide services it cannot pay for and to enable them to offer many more services and experiences than they would otherwise be able to provide"* (volunteer, hospice 22). In common with the previous two groups, they also recognise the importance of volunteering in the sustainability of the hospice. The majority of respondents from this group strongly agreed or agreed (97% - 72% strongly) that the hospice would not be able to provide the service it does without volunteers. One of the main reasons for volunteer involvement identified by the volunteers themselves was sustainability. Thirteen comments related to the hospice not being able to

function without volunteers. These came from adult hospices, children's hospices and organisations which provided services to both. "*The hospice would not be viable without volunteers"* (volunteer, hospice 24).

A new theme that emerged only from this group was a perception from 12 respondents that the hospice involved volunteers to support staff and free up their time for other duties. "*It helps the paid staff concentrate on their own jobs while volunteers are able to help 'lighten the load'"* (volunteer, hospice 24) and "*to allow nursing staff to concentrate on nursing care by carrying out ordinary tasks"* (volunteer, hospice 1). Additionally one volunteer recognised that the hospice was "the concept of volunteers" (volunteer, hospice 11).

When responses were again broken down by hospice type and by country there was a strong consensus across all questions. There was only one exception. Fewer volunteers in children's hospices strongly agreed or agreed (67%) that volunteers were important to patient care (adult 96%, both 96%).

3.4.3 Volunteer Responses - Public and community involvement

Respondents were then asked for opinions on the role of volunteers in public and community involvement. A breakdown of these responses by hospice type is shown in Table 3.6 and by country in Table 3.9. There was strong agreement or agreement that volunteers came from communities local to the hospice (85%), that they helped to embed the hospice in the local community (94%) and that volunteers raised awareness of the work of the hospice in communities

(99%). There was strong agreement or agreement that volunteers can help to reduce the fear that surrounds hospices (89%) and that volunteers make it easier for people to access the services of the hospice. However volunteers were less convinced that they help the community to talk about death and dying (64%), but interestingly 75% believed that they increased people's ability to support people in the community at end of life. Volunteers' views indicated that volunteers brought the views of the community into the hospice (85%) and 93% believed that volunteers have a lot to offer in helping the hospice with community engagement. However, when asked why hospices involved volunteers, unlike senior staff and trustees, very few volunteer respondents gave the reason as the development of links with the local community or as ambassadors for the hospice.

Responses from volunteers were again compared across hospice type and country to identify similarities and differences. Fewer volunteers in children's hospices strongly agreed or agreed (43%) (as opposed to adult (63%), or both (73%)) that volunteers help communities to talk about death and dying or that volunteers increase community capacity to support people at the end of life (57%) (adult 81%, both 73%). A lower percentage of adult hospice volunteers strongly agreed or agreed (79%) that volunteers brought the views of the community into the hospice (children's 83%, both 89%). There was also a significant difference in views between children's hospice volunteers and their counterparts in other hospices around volunteers helping hospices to become more engaged in their communities. Only 67% of children's hospice volunteers strongly agreed or agreed compared with adult hospices (90%) or both (95%).

There was, however, more agreement between English and Scottish volunteers with general consensus on all but two questions. A lower percentage of volunteers in Scotland strongly agreed or agreed (57%) that volunteers help people in the community to talk about death and dying (England 88%) or that they increase people's ability to care for people at end of life in the community (71%) (England 91%).

3.4.4 Volunteer Responses- Further roles for volunteers

Volunteers were also asked for their views about how volunteering might provide further support to the hospice. A significant number of volunteers chose not to respond to this question with only 60 responses from a possible 173. However, there was a range of responses and suggestions. The most common theme to emerge from a total of 20 respondents was that there was not much more that volunteers could contribute or that "more of the same" was what was required. One respondent cautioned that: *"There comes a time when the community are unable to sustain the requirements of the hospice for additional volunteers"* (volunteer, hospice 20).

The second most frequent suggestion (16 respondents) was about raising awareness variously of the hospice and the services it provides, of the need for funds and for volunteers. Awareness-raising was suggested not only within local communities and the public, but also through volunteer networks of family and friends, patients and families. More volunteers becoming involved in fundraising was a recurring topic as was more involvement in care.

Suggestions for the latter included: home visits, sitting with patients at the end of life, personal care, feeding patients and more social support for patients and families. Other suggestions included volunteers taking on more responsible roles such as team leaders for volunteers, contributing to decision making, more engagement with management and trustees, support with *"reviewing and writing business documentation"* (volunteer, hospice 9), assistance with audit and compliance; and "*Visit other hospices to compare services they offer and improve their own service and share the best of good practices*" (volunteer, hospice 29). One respondent from the same hospice also suggested that volunteers could help in very practical ways. "*There are some repair jobs around the hospice that could be done by volunteers instead of paid tradesmen"* (volunteer, hospice 29).

Interestingly there were some contrasting views with respondents indicating that personally they could do no more whilst others commented that volunteers could *"actually volunteer"* (volunteer, hospice 19) or " *Adopt the attitude that there is a lot more to volunteering that saying 'I am a volunteer at the hospice' but not prepared to go the extra mile"* (volunteer, hospice 5). There were other comments which indicated that hospices might not involve volunteers' skills to maximum advantage. Other respondents from children's hospices, stated that volunteers could do *"loads if the skill set of the volunteers was identified and used"* (volunteer, hospice 19) and "*the hospice could allow volunteers to use their own initiative more often"* (volunteer, hospice 23).

3.4.5 Summary of findings from volunteers

Overall, responses from volunteers give an impression of a group which recognise their contribution in a slightly different way to that of senior staff and trustees. Volunteers, in common with senior staff do not view the engagement with trustees as being as strong as the trustees findings indicate that it is. However, there are clear differences across hospice types and countries about trustees and trustee engagement. Findings suggest that volunteers also see themselves as being an important and integral part of the team and that they perceive volunteering to be important to patient care and support, enhancing the quality and range of services offered. Volunteer findings support those of senior staff and trustees in relation to their importance in making strong links with local communities, however they are less likely than the other two groups to agree that volunteering plays an important role in community capacity building and public education. Once again, there are some differences across hospice types and country about the role of volunteers and community engagement. Findings indicate that volunteers view themselves very much as being there to save money and to support staff, and to ensure hospice sustainability, with slightly less emphasis on supporting patients and families. However, they also see new and different possibilities for more volunteer involvement in the care and support of patients in the future.

Chapter 4 Discussion of Findings

4.1 Contextualising quantitative findings

Before discussing findings from the three groups of respondents, it is helpful to give some context to these. Findings were analysed across all hospices and were then broken down by senior staff, trustee and volunteer responses, by hospice type and also by country to explore similarities and differences. Findings were also considered by hospice size but there was little evidence to suggest that this influences attitudes to volunteering. There is a good geographic spread of participating hospices in Scotland and England with a balance of city hospices and those in more rural settings. However, as previously identified in Chapter 3, 3.1, there were no respondents from Wales and Northern Ireland and thus it is not possible to draw conclusions specifically about these countries. These findings apply only to 32 hospices and as such are not generalisable across the UK. Despite this, however, the research produced a rich source of data from 287 respondents and has identified future areas for research. Hospices which did not take part may wish to try testing these findings for themselves. The outcomes may still have a broad resonance as hospices are structured in a similar way throughout the UK. In Scotland, however, 75% of hospices took part in the study and it is likely that the findings from this study may be applicable to most if not all, Scottish hospices. Only a few children's hospices took part so caution is required in making assumptions about the wider applicability of findings in this area. Consequently, I shall consider only broad patterns and trends. As there was only one hospice with

no inpatient facility that provided only day and home care, it is not possible to make any comparisons with like organisations. The majority of hospices taking part were adult hospices. This is perhaps unsurprising as the largest group of hospices in the UK are adult hospices, with a smaller number of children's services and an even smaller number of services providing care for both adults and children.

A number of questions in the study produced quantitative data which was intended purely to give context to the qualitative findings. No statistical significance is inferred. These questions related to the number of beds, staff and volunteers in the hospice. There were a few respondents from the same hospice who gave inconsistent statistical information for the organisation. In these cases I undertook a further check with the hospice website, and other publically available information such as Annual Report and Accounts to seek further clarification. This, however, was not always available and where there was further disparity, I had to consider how current these information sources might be. In two instances I contacted the hospice directly. In all cases, where there was doubt, I was able to confirm the accuracy of the data given. It is clear, however, that caution must be exercised in making any statistical deductions from the data. Nevertheless, I believe that this information is still helpful in exploring whether there is any discernable relationship between the size of the hospice, the number of staff and volunteers.

It is probably unsurprising that there is mixed evidence of trends linking hospice size, measured by bed numbers, and the number of staff, as shown in Figure

3.1. It might be concluded that there are optimum ranges for staff to bed ratios. However, this is a fairly crude measurement and does not allow for the complexity of patient needs and their subsequent dependency level, or the skill mix within the staff team. Hospices are all independently managed and run and this is therefore likely to create differences between services. The range of services offered by the hospice beyond inpatient care, for example: day-care, care at home and the size of retail and fundraising operations will also affect variations in staff numbers. However, it might be concluded that the larger the hospice, the greater the need for larger income generation support services. In addition, there may be some influence on staffing levels arising from hospice funding and the availability of other staff not employed by the hospice e.g. NHS staff spending time in the hospice as part of training or agreed rotation. The size of the voluntary service may also have an impact. What is evident from the data as demonstrated in Figures 3.2 and 3.3 is that there are some trends between the number of beds and size of the volunteer team, but not between the number of staff and the number of volunteers. Again, volunteer numbers may be influenced by many factors. These may include the size of the organisation, organisational and staff attitudes to volunteering, the stage of development of the volunteer programme, how widely volunteers are involved in the hospice and the availability of volunteers from the local area. As previously mentioned it would appear from Table 3.1 that the larger children's hospices (over 10 beds) have fewer volunteers than adult services with the same number of beds. This would seem to give some support to findings from Burbeck et al. (2013), Pastor (2010) and Scott (2009) who suggest that children's hospices seem more hesitant to involve volunteers than adult hospices. It would be

interesting to study this area in more depth and to identify more clearly if there are patterns, frameworks and trends linking bed numbers, staff numbers and numbers of volunteers and to understand the reasons behind these. As discussed earlier, a further breakdown of data was undertaken to explore trends between bed, staff and volunteer numbers in children's hospices, and to identify any similarities and differences between these and hospices as a whole. Despite the small numbers in the sample, the graphs shown in Figures 3.3,3.4,3.5,3.6 overall were broadly similar to those in Figures 3.1-3.3. However, it is clear that there is a stronger correlation between the number of beds and number of staff, number of beds and numbers of volunteers in hospices providing children's services as shown in Figures and 3.4 and 3.5 respectively. The graphs show that generally if there are higher numbers of beds, then there are likely to be more staff and volunteers. However, as can be seen from Table 3.1, this does not always hold true. Conversely, there seems to be less of a relationship between staff and volunteer numbers in children's hospices as shown by the widely and randomly scattered points in Figure 3.6. It would seem, therefore, that there is some connection between the size of the hospice and the number of volunteers involved. This may be connected to the physical size of the hospice building, the infrastructure in terms of shops and fundraising, and also the range of additional services provided by the hospice such as day care and home care. These areas may also be smaller in comparison to a larger organisation, giving less opportunity volunteer involvement. Numbers of volunteers will also be strongly influenced by the amount of time donated by each volunteer. For example, if volunteers come in on average for only one or two hours at a time, this will significantly increase the

number of volunteers required to support the service compared with a hospice where volunteers give half or full day. The quantitative findings have been valuable in giving some context to other findings. I will now move on to discuss the findings from an integrated qualitative and quantitative perspective.

4.2 Findings from both the qualitative and quantitative perspective

There is clear evidence from the literature review that the impetus for the founding of hospices of all types came from volunteers. Those initiating the development of hospices did so in a voluntary capacity. Findings from my study would support this, as a number of respondents stated clearly that their hospice had been founded by volunteers and gave this as one of many reasons for continuing to involve volunteers today. In addition, respondents indicated that volunteers had played a significant role in the development, culture and ethos of those organisations. This is supported only in part by the literature. Whilst Scott et al. (2009); Clark et al. (2005); and Sallnow (2010) are clear that hospices have a significant history of volunteer involvement, there was little recognition in the literature that the early founders of the hospice movement were volunteers. Neither was there an understanding of the influence which volunteering had on organisational culture. Interestingly, the influence on ethos and culture was mentioned by a number of respondents in the study as the reason for involving volunteers. If anything, findings from the literature relating to the organisational development of hospices would suggest that hospices are seen less as voluntary organisations, and more as part of mainstream health care as suggested by James and Field (1992).

However, findings from senior staff, trustees and volunteers indicate that volunteers have a key role to play in enabling hospice services to function effectively. This would support my stages of organisational development which I adapted from Fisher, Rooke and Torbert (2003) and applied to hospices (as shown in Table 1.8). This demonstrated the changing role and influence of volunteers on the development of hospices at all stages of development. This may have significance for the future development of hospices. The role of volunteers clearly has an influence on the ethos, governance and sustainability of hospices, as supported by my findings. If independent hospices are seen as part of mainstream health care, rather than as voluntary sector organisations, this may lead to a general public misunderstanding of the uniqueness of their role and the holistic care which is provided. Above all, the overriding perception may be that services are fully funded from statutory sources. Whilst there may be clarity about this in communities local to hospices, this may not be widely understood by the public at large and as such may have an influence on ability to attract funds and volunteers in the future, thus affecting sustainability.

My study has identified that hospices depend on volunteers for the effective functioning of many organisational areas. Davis-Smith, (2004), Gaskin (2003), Guirguis-Younger and Grafanaki, (2008) and Morris et al. (2013) all suggest that organisational attitudes and structures often inhibit the effective management and integration of hospice volunteering, resulting volunteers not feeling valued as part of the team. They also suggest that a range of organisational and management approaches are required to ensure the success of volunteering programmes. Whilst my findings suggest that

volunteers do feel an integral part of the team, they also identify that, in just under half of the hospices that took part, volunteers do not contribute to the development of hospice strategy in which volunteering is explicitly mentioned. This might suggest a paternalistic attitude to the development of volunteering in some hospices and/or a failure to take account of volunteer views in the future development of services. This may also suggest a 'top down' approach to the management of volunteers. According to Rochester et al. (2010), this approach may not be sustainable. They conclude that this is because such models often fail to take account of changing expectations of volunteers. Addington-Hall and Karlsen (2005a & 2005b) assert that hospices must take account of volunteer views when planning developments as they may well represent the views of the general public.

The study explored the way in which volunteering is understood by senior staff, trustees and volunteers in five particular areas: the volunteering contribution to 1-governance, 2-the hospice, 3-commmunity engagement, 4-why hospices involved volunteers and 5 what more volunteers could do to support the hospice. Findings from the study fell into four main themes and this section will discuss the findings under the four headings of: governance, service delivery. hospice economy, and community engagement.

The literature suggests that reliance on volunteering is not purely historic and that hospices continue to depend on volunteers today. Davis-Smith (2004), Guriguis-Younger, Kelley and McKee (2005) and Scott, Howlett and Doyle (2009) all assert that volunteers are vital to the delivery of care and support to

patients. Indeed Guriguis-Younger, Kelley and McKee (2005) believe that they are one of the most consistent elements of hospice care and my research would tend to support this view.

4.2.1 Governance – a strategic perspective

The purpose of the governance questions was to explore how volunteering was understood in relation to governance and strategy. These questions sought the opinions of senior staff, trustees and volunteers in the following areas: recognising and understanding the role of trustees, engagement between trustees, staff and volunteers, volunteering and the strategic plan, and the relationship between volunteering and ability to provide services. This is one area of the study generated the greatest divergence of views as shown in Table 3.4. Overall, there was little recognition of the dependence of hospices on volunteering for the governance of the organisation. Whilst there is clear recognition that trustees are volunteers, only one respondent, a trustee, identified volunteers as being important to the governance of the hospice, stating that their hospice involved volunteers because they were important to the delivery of the strategic plan. However, no respondents commented on the role of trustees in relation to governance and strategy. This would lead me to conclude that the role of trustees may not be well understood and would support findings from Turner and Payne (2008). They assert that hospice governance could be improved and that there is a need for improved comprehension of the work undertaken by hospice trustees.

Trustees who took part in my study are strongly of the opinion that they engage well both with staff and volunteers. However, there is a divergence of views between trustees, senior staff and volunteers. Staff and volunteers do not fully agree with the views of the trustees in relation to their engagement with them. There are also differences in perceptions across hospice type and in Scotland and England. Fewer adult hospice staff agreed that there is understanding of and engagement with trustees. When comparing hospices by country, this also holds more true for hospices in Scotland than their English counterparts. Fewer trustees and volunteers in children's hospices agree that volunteer views are sought. The reasons for this are unclear, especially as some responses are from senior staff and it might be considered that they would have a regular engagement with trustees and that their views would be sought more frequently than those of volunteers. With regard to volunteers, this may be due to the numbers of volunteers in each hospice being significantly greater than the number of trustees. This may make if difficult for trustees to engage with every volunteer. Consequently some volunteers may have little contact with trustees. Additionally, because of the very part-time nature of volunteer involvement, trustees are more likely to have opportunities to meet and develop relationships with staff. Engagement between trustees and volunteers could be addressed both through training and improved communication to foster greater understanding of each other's roles, responsibilities and activities. One approach might be to develop opportunities for trustees to attend volunteer events, where they may meet larger groups of volunteers in an informal setting. Shared induction programmes for staff, trustees and volunteers would also deepen knowledge and understanding of respective roles and responsibilities.

This would help to facilitate dialogue and engagement between the groups. Given the significance of volunteers in terms of numbers and contribution, it is important that trustees have an opportunity to hear volunteers' views and ideas. Both are volunteers, albeit with different responsibilities and it is important that there are effective channels of communication which enhance both strategic and operational aspects of the service.

As trustees are responsible for the overall direction of the hospice and senior staff accountable for the effective achievement of organisational goals, I was keen to explore with both groups whether volunteering is viewed as a strategic resource. Apart from a recent report to help the Hospices from the Commission on the Future of Hospice Care (2012b) suggesting that volunteers are key to hospice strategy to enable them to increase both the influence and scope of services, there is little evidence from the literature to suggest that the strategic importance of volunteers is widely recognised.

The absence of information in the literature would suggest that little attention is given to strategic planning for volunteering. Interestingly, there is some evidence in my study to contradict this as most hospices indicate that volunteering is explicitly included in their hospice strategy plans. Findings also suggest that that the value of volunteering input is measured, although this was less prevalent in children's hospices and in hospices in England. The majority of hospices state publicly why they involve volunteers, regardless of hospice type or geography.

Almost all respondents perceive volunteering as important to the hospice in enabling the provision services, regardless of hospice type of geography. Initially, this may be viewed as a positive finding and would suggest that there is recognition of the importance of volunteering as a strategic resource. However, on closer examination, evidence suggests that approximately half of the hospices which took part engaged volunteers in the strategic planning process. However, there are geographical differences, with almost three quarters of Scottish hospices indicating that volunteers contribute to the strategic planning process. This would suggest that in some hospices there is a 'top down' approach to planning for volunteer involvement and precludes contributions and ideas from volunteers themselves about the future direction of the organisation. I would suggest that this is a significant omission and excludes the perspective of a large proportion of those involved in the delivery of service and achievement of objectives. This might suggest a hierarchical approach to volunteering in hospices. Anecdotal evidence suggests that some volunteers do not wish to be involved at this level. However, my professional experience in my own organisation would suggest that this is not true for all volunteers. Indeed we have successfully included volunteers from different parts of the organisation in developing our strategic plan. It would be interesting to explore further how many hospices involve stakeholders in their strategy planning process to give an insight as to whether findings from this study apply only to volunteering.

4.2.2 The volunteering contribution to service delivery

How volunteers are understood by hospices was further explored through questions relating to their impact and influence on the delivery of services as illustrated in Table 3.5. This section elicited strong agreement from all respondents, (regardless of hospice type or geography) across most questions. Almost all senior staff, trustees and volunteers agree that volunteers are recognised as an integral part of the professional team. This is a very positive finding which is contrary to previous research. Davis-Smith (2004) suggests that volunteers do not always feel valued, or an integral part of the team. Gaskin (2003), Davis- Smith (2004), Addington-Hall and Karlsen (2005a & 2005b) and Barron (2008) all suggested that attitudes towards volunteering had changed little in recent years. Andersson and Ohlen's study (2005) concluded that volunteers needed to be fully recognised as part of the team in order for them to feel truly valued. However, it is important always to retain the essence of volunteering which is about free will, creativity, and spontaneity. Findings from this research have indicated that volunteers complement and enhance the roles of paid staff. It is important, therefore, in considering the further development of volunteering as part of the professional team in hospices that the uniqueness of volunteering is not lost by attempting to regulate and train volunteers to become 'pseudo-professionals'.

Findings from my study might, therefore, indicate a positive change in attitude to volunteers. However, this is a study involving only a small number of hospices and involved only a senior staff perspective. There would be value in

further research to explore this more widely with a broader group of staff and also volunteers to ascertain whether this view is held more widely. It would be interesting to explore whether volunteers now feel more valued than previous studies would suggest.

It is clear from my research that all sizes and types of hospice are reliant on volunteers for the delivery of services. This may be for a number of reasons. As shown in Table 3.1, there is clear evidence of a much higher percentage of volunteers than paid staff in hospice organisations which took part. Consequently, this constitutes a significant workforce resource and is supported by the literature. Help the Hospices (2011) suggest that there are 4,000 paid staff and 100,000 volunteers in UK hospices. However, my research indicates that it is not only the significance of the workforce resource which indicates dependency. My study supports Gurgius-Younger, Kelley, and McKee (2005), Faulkner (2005) and Scott (2006a, 2009), indicating that volunteers are important for the skills and experience that they bring, thus contributing to the care and support offered to patients and families. There is a strong consensus from all respondents that volunteers bring expertise that adds to that of paid staff, thus increasing the skill mix of the multi-disciplinary hospice team. Almost all respondents agree that volunteers are important to the care of children and adults, and the support offered to their families. However, this is not supported by the findings shown in Table 3.11 which indicate that less that one quarter of the volunteers taking part in this study had roles which involved patient care. In addition, when asked what more volunteers could do to support hospices, respondents indicated that volunteers could become more involved in the care

of patients and families. This implies that volunteers are not widely involved in providing this support at present. Experience from my professional practice, including anecdotal evidence from a range of hospice networks, would certainly support this view. It would be true to say that there is a level of reluctance amongst professionals to involve volunteers in patient care.

A number of respondents in my study highlighted the de-medicalisation of care as a reason for the involvement of volunteers. They also stated that volunteers brought a more personal approach to care and increased the quality and range of services available to patients. This supports Gurgius-Younger, Kelley, and McKee (2005), Faulkner (2005) and Scott (2006a, 2009) who also identified the role of volunteers in bringing a more social approach to care. Whilst all groups stated that a key purpose of involving volunteers was to bring diversity to the staff group in terms of skills and experience and to extend and improve the quality of care and support, only staff and volunteers recognised the role of volunteers in making care more personal and less clinical. This perhaps is unsurprising as these two groups are more likely than trustees to witness the impact of volunteering on patients and families. In addition, this suggests that volunteers are important to the delivery of a truly holistic model of care, bridging the gap between the medical and social models of care. This is further supported by the finding discussed in Chapter 3 which suggested that volunteers help make hospices more accessible to patients and families by reducing the fear and the taboos which exist around hospice care.

Interestingly, however, volunteers are the only group who believe that they are involved in order to support staff and to enable them to concentrate on more specialised areas of care. This was not mentioned either by senior staff or trustees who clearly perceive the volunteer role as enabling cost-effective services, supporting patients and families, and other areas of service delivery. This deserves further exploration, as it is unclear as to whether this should be construed positively or negatively. Volunteers may perceive themselves in this role as a result of a hierarchical approach to volunteering. Alternatively, many volunteers may be content to help without taking on any significant responsibility. It may be that their skills may not enable them to give care but may involve them in providing support to staff in many other ways. Conversely, however, there was evidence in this study that suggested that in some instances volunteers' skills are not always used to best advantage. Volunteers also may perceive that enabling hospices to be cost-effective is a good use of their time and energy. There is a possibility that the volunteers' perceptions come from the messages that hospices give about volunteering. Volunteer perceptions may also arise from a hierarchical approach to their management, organisational structures and approaches.

Other findings from this research, however, would suggest that not all volunteers are content only to play a supporting role. When asked what more volunteers could do to support hospices, a small number of volunteers suggested that their skills could be used more effectively and that they could become more involved in supporting work at management level. Other suggestions from all groups related to a greater involvement in patient care,

including basic nursing care, personal care, feeding patients, chaplaincy and befriending. Hospices clearly value the services which volunteers already provide and are happy to continue to develop these in the direction of more hands on care. Alongside this, however, there was a clear suggestion that volunteer skills were not being utilised for maximum effectiveness. The inference was that volunteers had more skills than their roles permitted them to use. New developments which involve volunteers more directly in patient care and support, and in roles with higher levels of responsibility, might go some way to address this.

What must not be overlooked, however, is the level of involvement that individual volunteers want. Hospices need to understand more about the volunteer perception that their role is to support staff, as volunteer motivations must be clearly identified and considered if volunteer expectations are to be matched effectively with organisational need.

Almost all staff agree that they consider how volunteering might contribute to any new projects and the majority of this group state that they know how may volunteers will be needed to deliver the service the following year. There was some divergence of views in children's hospices and between hospices in Scotland and England. Only half of the respondents from children's hospices agreed with this and fewer hospices in England agreed than their Scottish counterparts. Yet not all senior staff respondents agreed that there was a plan in place specifically for volunteering. Just over half of the adult hospices taking part agreed with this whilst a lower number of hospices in England agreed when

compared with their counterparts in Scotland. These findings seem surprising, as without a plan identifying areas of development, it would seem difficult to quantify the required volunteering resource. These findings pose some interesting questions. Quantitative findings shown in Figure 3.1, demonstrate that there is a much higher percentage of volunteers than paid staff involved in hospices and that they are, therefore, a significant workforce resource. Whilst volunteering is included in hospice strategy and volunteers are recognised as an integral part of the hospice team, it appears that, for some hospices at least, there is no planning in place for the development of voluntary services. This suggests that some hospices may lack a framework to ensure effective forward planning, development, support and measurement of the impact of this large resource. It seems surprising not to have a plan in place to guide and focus the activities of a group so central to the delivery of services. I would suggest that it is unlikely that this would be the case for other key resource areas such as care services and fundraising.

4.2.3 The volunteering contribution to the hospice economy

Not only are volunteers crucial to the delivery of services as an integral part of the multi-professional team, my research strongly suggests that volunteers also make a significant contribution to the hospice economy in a variety of ways. This holds true for all hospices and across Scotland and England. There is significant evidence from my study to indicate that volunteers are vital both to income generation and cost effectiveness of services and that their donated time makes a significant economic contribution, supported by Gaskin (2003)

and Help the Hospices (2006). Help the Hospices (2006) estimated that the value of volunteering to hospices in the UK is £112m and predicted a 23% increase in costs if hospices had to pay for the work undertaken by volunteers. My study did not attempt to address the actual economic value, but rather whether or not his was calculated and used by hospices as a tool for future volunteer resource planning.

There is strong agreement that the volunteering contribution enables services to be cost effective. This, in turn, enables hospices to provide a range and diversity of services which might otherwise not be possible.

There is overwhelming agreement that volunteering helps to make hospice services sustainable. Wilson et al. (2005) suggested that volunteers could be key to the sustainability of organisations and findings from my research would strongly support this view. Further support for this was evident when respondents were asked why hospices involved volunteers. Overwhelmingly, senior staff, trustees and volunteers all agree that key reasons for involving volunteers is to help hospice services to remain cost - effective and to generate income. A number of respondents across all groups reinforced findings around sustainability stating that their hospice involved volunteers because without volunteers, they would have to close. This would appear to be a strong validation of the importance of the contribution made to hospices by volunteers. Volunteers also saw their purpose primarily in economic terms with almost all respondents commenting on saving money and maximising resources. Many were of the opinion that the hospice depended heavily on their contribution. It is not clear why volunteers should place so much emphasis on the financial

perspective. There is no reason to see this as either a negative or positive finding. Perhaps this is the message that volunteers take from or are given by hospices talking about the economic value of the volunteer contribution. It may be that in some cases it is openly stated that volunteers are involved in order to minimise costs. Volunteers may even be pleased that they enable services to save money and in some cases ensure the survival of the organisation. This may be a validation of the importance of the time they donate. From my own professional experience, I know that volunteers are very critical of any hospice expenditure which they believe is unnecessary and this may link to their own desire to maximise resources by volunteering.

There have been numerous studies of volunteer motivation and there is no evidence to suggest that economic reasons are a motivating factor for volunteering. Perhaps, however, when a person invests time without seeking financial gain, their interest in cost effectiveness is heightened and it may indeed become an additional motivation to continue to support the cause. Knowing that a service depends on volunteering contribution for continued sustainability might be considered to give volunteers a sense of value and importance. Alternatively this could be seen as a pressure to continue to volunteer, even a form of emotional blackmail. It might also be that the message that volunteers are involved primarily to enable cost-effectiveness negates the skills and experience which they so clearly bring to the organisation, and which findings would indicate is valued by hospices. Although the number of hospices in my study is small, findings would suggest that there would be merit in further researching the link between volunteering and

organisational sustainability. It would also be interesting to understand why volunteers are more strongly of the opinion that they are involved primarily to save money and whether this has a positive or negative impact on their motivation. Further, it is important for hospices to understand this area more fully to ensure that volunteer motivations are understood and that their expectations are matched effectively to organisational needs.

Time donated by volunteers also has an economic value to organisations. Whilst just over half of the hospices in the study indicated that they calculated this and used the value to inform future planning, there was a variation by hospice type and geography. Many fewer adult hospices and hospices in England calculate the economic value of volunteering, but approximately half of all hospices used the information for planning purposes. Measuring the economic value of volunteering is only one method of assessing the impact of volunteering. However, it does give the opportunity to explore the economic return on investment of the volunteer contribution and this can provide valuable information for future service planning. It can also be used as a guide to consider whether there is sufficient resource invested in volunteering. An overly high return on investment might suggest that inadequate resources were in place to support the service.

In considering the economic impact of volunteers, it is also important to consider the costs of volunteering to an organisation and so budgeting for volunteering was also explored. Most respondents in all groups were of the view that a budget was in place for volunteering and that the costs to the

hospice are calculated. Only adult hospices and hospices in Scotland were less likely to calculate volunteering costs. Overall, this is a positive finding as often volunteering is considered by organisations to be a free resource. However, my findings indicate that the contribution of volunteers to hospices is considerable. Thus, there requires to be consideration at a strategic level of the needs of the voluntary service in terms of leadership, support and development opportunities in a similar way to that of paid staff. Given that hospices report a high level of dependence on volunteering for service delivery, income generation and sustainability, it is positive that they recognise the need for investment in the voluntary service. However, there is no information from this study to indicate whether this is adequate to meet the needs of the service. A total of twenty-seven respondents across all groups stated clearly that without the involvement of volunteers their hospice would be unable to survive. Fourteen of these were senior staff and trustees. This is a very powerful statement of the significance of volunteers to the sustainability of independent hospices in the UK.

4.2.4 Volunteering and community engagement

Without a demand for services, hospices would have no reason to exist. This demand comes from patients and families in communities local to the organisation. Organisations such as hospices are also dependent on their community for a significant proportion of their income, public support and goodwill, and the recruitment of staff and volunteers. The literature suggests that volunteers enable strong, reciprocal links between organisations and their local communities (Big Society (2010, Big Society Overview 2011, Hawkins &

Restall (2006)). This was strongly supported by my research findings from trustees and senior staff who reported volunteers as an important element of their relationship with their local community. Cited as a key reason by hospices for involving volunteers, this is supported by McCurley and Lynch (1998) who identified links to communities as a reason why organisations involved volunteers. The literature also identified government recognition of the importance of community engagement both generally (Big Society (2010), Active Communities (2001)), and specifically in providing palliative care in the community (Palliative Care and End of Life Care Strategy for Northern Ireland (2009)). I was, therefore, keen to explore how volunteering was understood in relation to community involvement. Questions in this section of the survey explored the role of volunteers in engaging the public with the hospice cause, addressing taboos around hospice care, death and dying and capacity building within communities local to the hospice. Again there is a strong consensus among respondents in this section of the survey as illustrated in Table 3.6.

It is clear from this study that volunteers play a significant role in embedding hospices in their local communities. There is strong agreement from all groups that trustees and volunteers are mainly drawn from areas local to the hospice and a belief that volunteers play a significant role in raising awareness of the work of the hospice in the community. However, fewer trustees in children's hospices agreed with this, indicating that these organisations may draw their trustees from a broader geographical location. Almost all staff and trustees and a majority of volunteers indicated that volunteers bring the views of the local community to the hospice and that they had a lot to offer in helping the hospice

to become more engaged with the communities which it serves. Fewer volunteers in children's hospices agree that volunteers can help the hospice to become more engaged in the community. Reasons for this are not clear, but may relate to the roles that volunteers play in children's hospices which are often more peripheral than their adult counterparts. This may support findings from Burbeck et al. (2013), Pastor (2010) and Scott (2009). Volunteers are generally ambassadors for their hospice, talking about what motivates them to help and about how rewarding they find their involvement. Almost all respondents agree that volunteers help to reduce the fear surrounding hospice care and consequently make it easier for people to access and use the services of the hospice. However, fewer senior staff in adult hospices agree when compared with senior staff in other hospices. This study would suggest that volunteers already play an important role working with the public to dispel myths about hospice care and contribute partly to reducing the taboos which often exist around death, dying and bereavement. Over half of respondents agreed that volunteers facilitate conversations about death and dying with people in the local community, making this less of a taboo subject. Volunteers have many informal conversations within their networks which may include families, friends and work colleagues. These conversations have the potential to change attitudes to hospices, death and dying. It would be interesting to explore this area in more depth and to understand how these skills might be further enhanced to empower the development of this area.

There was also general agreement from all groups that volunteers increase the ability of communities to support people at end of life. However, it was also

recognised that volunteers had even more to contribute to all aspects of this area in future. One group with differing views was Scottish hospices. Fewer of this group agree that volunteers help to address taboos around death and dying, and increase community capacity to support people at end of life. It is not clear why this should be.

There is, however, a dichotomy between these findings and some of the reasons given as to why hospices involve volunteers. Community engagement was given as a motive for involving volunteers by senior staff and trustees. There was, however, much less emphasis on this from the volunteers themselves. Where staff and trustees felt that volunteers were important in making links with the community, giving ownership of a local resource and facilitating awareness and shared understanding of the hospice, this was apparently of much less importance to volunteers. It is interesting to note that volunteers do not seem to see themselves in this way, given that they are part of the local community. Perhaps this is because they have a more individual view of their role, whilst staff and trustees see the collective contribution, impacts and possibilities. It may be that this reason for the involvement of volunteers, whilst clearly seen as important by senior staff and trustees, is not communicated either effectively, or indeed at all, to volunteers. It could also be, therefore, that whilst volunteers recognise their contribution to community engagement, that they do not recognise this as a reason for their involvement in hospices. This study found that there is clearly still much that volunteers can do to support hospices and a willingness to develop roles in care. One respondent cautioned that there was a limit to the amount of volunteering that local

communities could sustain. This is an interesting observation which deserves further consideration. The nature of the local community may considerably influence the availability of volunteer resources and subsequently affect the sustainability of the organisation.

4.3 Summary of discussion

There is clear evidence that many more volunteers than paid staff are involved in hospice organisations, and that this applies, regardless of geography, both to adult and children's hospices and also to services providing care to both adults and children. Whilst there would appear to be some link between the hospice size and number of volunteers, it would seem that hospices have a very individual approach to the involvement of volunteers, with varying perceptions about the numbers needed to support the delivery of services. Whilst this may reflect individual organisational attitudes and local demographics, it could also suggest a lack of structured planning for voluntary services. It is clear that volunteers undertake a wide range of roles within the hospices surveyed.

In considering the role of volunteers in governance, whilst trustees believe that they have good engagement levels with staff and volunteers, it is apparent that these two groups do not fully agree with this and there are differences across hospice types and locations. Volunteers appear to have a low level of engagement in relation to strategic planning and little account seems to be taken of their views and ideas for the future direction of the hospice. Whilst this deserves further investigation to explore this more fully, it could suggest a

hierarchical approach to strategy and a lack of stakeholder involvement in planning. There is also contradictory evidence in that, while trustees are recognised as volunteers, there is little evidence to suggest that volunteers are considered to be important to the governance of hospices. There is clearly a disparity here between espoused theory and theory in practice.

Volunteers are, however, clearly recognised as a valued and integral part of the hospice team, a finding which has not been identified by previous research. This may suggest a positive shift in attitudes towards volunteers but requires further study to explore whether this view would be supported by staff at all levels of the organisation. Volunteers also multiply and enrich the skills of paid staff, however fewer than half the organisations taking part had a plan in place to support the development of volunteering. This would suggest that there is no framework for the development of a significant organisational resource. It might also be considered that this is contrary to a hierarchical model of management. Still apparent, however, are barriers to the involvement of volunteers in care, across all hospice types. Interestingly, however, this is coupled with a recognition and willingness to develop the role of volunteers in patient care. This study also highlights the key role that volunteers play in the delivery of a holistic model of care, bridging the gap between medical and social models of care.

However, there is also overwhelming evidence that the perception of respondents is that volunteers are of economic significance to hospices. Volunteering is recognised for the impact made on income generation through

fundraising. Time donated by volunteers also enables hospices to be more cost-effective and provide a greater range and quality of services to those for whom they care. Volunteering, however, is understood differently by volunteers when compared with senior staff and trustees. Primarily, volunteers see the reasons for their involvement as reducing costs and supporting staff. It is not clear whether this should be construed positively or negatively. Neither is it evident whether this is as a result of messages given to volunteers either explicitly by staff or implicitly through their experiences of organisational approaches, management and staff attitudes. This area, therefore, deserves further study.

Volunteers currently play a significant role in the symbiotic relationship between hospices and their communities. Their role has an important public education dimension: raising awareness of the work of hospices, reducing the fear which surrounds hospice care and in making hospice care more accessible. This study suggests that volunteers also have a role in capacity building within communities around death, dying and bereavement. However, there is a disparity across hospice type and geography and volunteers do not perceive themselves in this way. Perhaps with further training volunteers could become an even more effective resource for hospices and communities. Their role in the education of the general public about palliative and hospice care, death, dying and bereavement could also be significantly enhanced.

It is clear that volunteers impact on many areas of hospice care and this study suggests that volunteering is inextricably linked with hospice sustainability

regardless of size, type or geography, and in a small number of cases, the ability of the hospice to continue to operate. It is important, however, that hospices continually monitor the many external factors which affect both the organisation and volunteering and which may subsequently impact on their sustainability. I will now consider whether the findings from my study support my theoretical model of organisational sustainability as shown in Figure 1.1 and also whether any subsequent modification is required.

Chapter 5 Conclusions and Recommendations

5.1 Comparison of findings with the theoretical model

The literature review, and my application of Fisher, Rooke and Torbert 's (2003) stages of organisational development to hospices led me to consider whether there were other factors which might sit alongside their framework in describing organisational sustainability. I consider sustainability to be a key consideration for organisational development. As previously discussed in Chapter 1, my theoretical model of organisational sustainability, shown in Figure 1.1, is based on conclusions drawn from the literature review. The model shows eight key Organisational Sustainability factors and the relationship between these and the external and volunteering influences which impact on these factors. The eight Organisational Sustainability factors are:

- demand for services;
- effective governance;
- responsive strategy and development;
- effective leadership and management;
- financial assets;
- human assets: skilled staff and volunteers;
- public support;
- effective partnerships – political, statutory, private and voluntary sector.

I was keen to explore whether my model would have application in practice and chose to use this as a framework to explore the relationship between

volunteering and the sustainability of independent hospices in the UK. The Organisational Sustainability and Volunteering Influences sections of my model informed the development of both the subject areas and the questions used in my survey with hospices. This allowed me to discover how volunteering is understood strategically by senior staff, trustees and by volunteers themselves. Data generated by the questionnaire allowed me to understand the impact of volunteering on four of the organisational sustainability factors: 1) governance, 2) service delivery, 3) hospice economy and 4) community engagement. Whilst my research did not focus specifically on the External Influences section of the model, I was able to draw relevant conclusions from literature findings about the ultimate impact of these on organisational sustainability. What is clear from both the discussion of findings and comparison with the literature review (Chapter 4) is that volunteering has a significant impact on these four sustainability factors drawn from my theoretical model. As previously highlighted, findings indicate a significant dependency on volunteering for governance, the range and quality of services delivered, the cost effectiveness of services, income generation and the value of donated time. Volunteering also plays a crucial role in embedding hospices within their local community. However, findings from the study indicated that volunteering had an influence beyond these four organisational sustainability factors. Volunteers as trustees have a key role in the development of a responsive strategy, and in ensuring effective leadership and management and volunteers in more operational roles provide support to professional staff. This would suggest that there is a good correspondence between almost all of the eight organisational sustainability factors and their interrelationships as shown in my theoretical model and the

experience of hospice organisations which took part in this study. Therefore, I can conclude that my model has applicability in practice.

As previously discussed in Chapter 4, findings also suggest that volunteering has an impact on most of the seven factors in the 'Volunteering Influences' section of the model: 1) the need for a supply of skilled volunteers, 2) trustees, 3) fundraising, 4) the economic value of donated time, 5) community involvement, 6) public education (about hospice care) and 7) volunteer satisfaction and retention. Evidence from my study also suggests that many hospices intend to develop their volunteering service, having identified a need for new care focussed roles, or in some instances recognition that they needed 'more of the same'. The literature provides compelling evidence of the effect that external influences such as national policy, changing demographics and society, the economic climate and changing volunteer expectations can have both on organisational sustainability factors and on volunteering itself. Whilst my study did not set out to explore this area in practice, two volunteer respondents identified that both volunteers and the community local to the hospice might not be able to sustain demands for additional time and people.

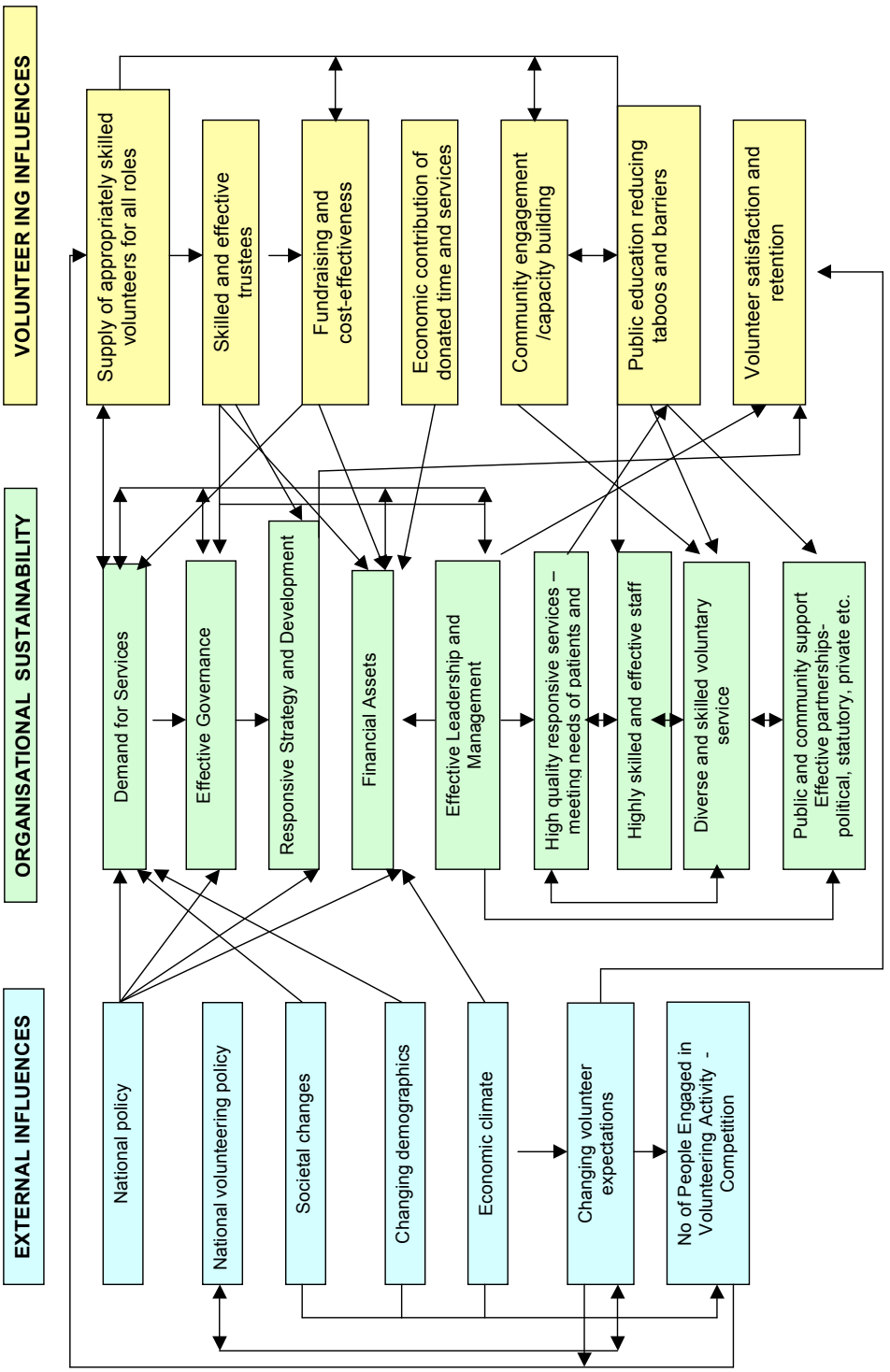

Figure 5. 1: Diagrammatic representation of Revised Theoretical Model of Volunteer Impact on Voluntary Organisation Sustainability

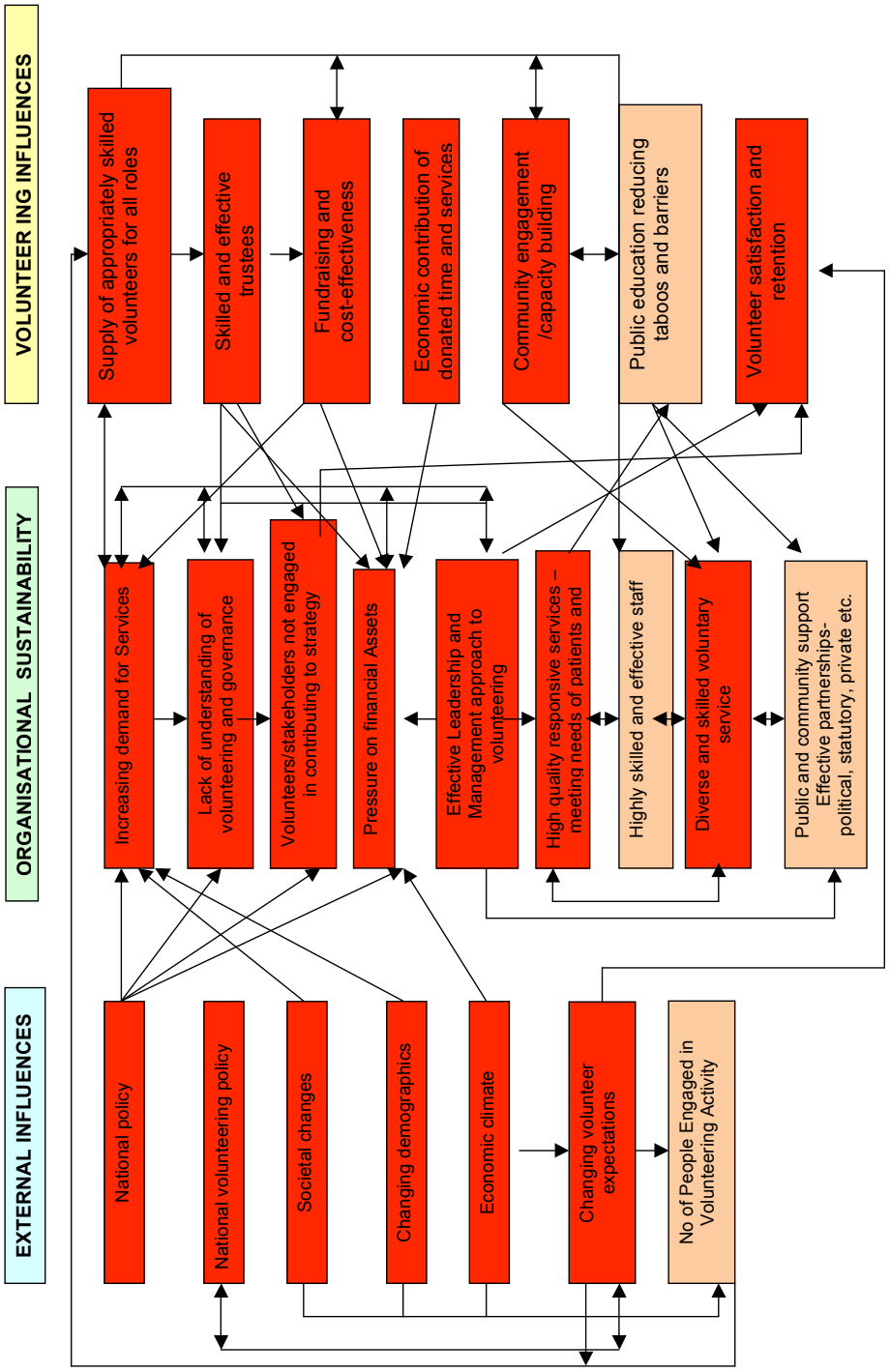

Figure 5. 2: Diagrammatic representation of Hospice Organisation Sustainability Risk Factors as identified by research findings.

I believe, therefore, that my theoretical model of organisational sustainability has close resonance with practice in the hospices which took part in this study. Having considered the findings from my research in relation to the model, I have subsequently made some revisions. Modifications have been made to all three sections: “External Influences”, “Organisational Sustainability” and “Volunteering Influences”. The revised model is shown in Figure 5.1. My reflections on the literature review suggested that there might be one element missing from “External Influences”. It is not only the fluctuating pool of volunteers that might be of concern, but the increasing competition from other organisations as government continues to promote volunteering which might prove to be a risk for factor for volunteer-involving organisations. On reviewing the model, two further areas appeared to be missing from the diagram; one in the organisational sustainability section “High quality and responsive services meeting the needs of patients and families” which was identified many times by all respondents in the survey. The second area in the volunteering influences section which I added was “Skilled and effective trustees” as this seemed to be an area which was less well understood as a volunteering influence by respondents in the study. Because of the significant dependence on volunteering identified in this study, I have separated the section on “Human assets” in the organisational sustainability section of the model. I have added “Diverse and skilled voluntary service” to represent the sustainability factors more effectively as identified by study. I have grouped some factors together and changed the wording of others to reflect my findings more closely.

Following this revision of my original model, I subsequently considered the potential volunteer impact risk factors for organisational sustainability as identified by my research. I have taken the revised model and highlighted the areas most at risk in red as shown in Figure 5.2. Those areas which carry a lesser risk are highlighted in orange. In the section “External Influences”, I consider that the literature has identified the areas coded in red as risks to organisations in the future with increasing demands for and changing expectations of hospice services, providing challenges for funding and the changing nature of tomorrow’s volunteers. I have left the area relating to the pool of available volunteers coloured orange, as, whilst statistics from the literature show fluctuating trends in the number of people volunteering, it is not clear whether the recent upward trend will be sustained. Coupled with the trend in the number of people engaged in volunteering, this will pose a risk to the supply of appropriately skilled volunteers; hence this has been coded as red in the “Volunteer Influences” section. The findings suggest that all except one of the factors under the “Organisational Sustainability” heading are risks for hospices and are influenced by external factors and by volunteers. I have identified “Highly skilled and effective staff” as less of a risk. It might seem surprising that this has been highlighted as a risk at all, however, findings from my study suggest that volunteers play a key role in supporting staff to enable them to fulfil their roles. Should there be a shortfall in the skills or number of volunteers available to hospices, this could subsequently affect the effectiveness of staff who currently depend on volunteers for the delivery of services. Based on findings from my study, I have concluded that all factors under the heading “Volunteering Influences” pose a potential risk to hospice

sustainability. This is because of the reasons that hospices are so dependent on volunteers for governance, fundraising, economic value of donated time, community engagement, and public education. As volunteer satisfaction and retention is also essential to the effective delivery of services and can be affected by a number of organisational approaches and attitudes, I have also identified this as a risk factor.

It should be recognised that alongside these areas of identified risk, volunteers also increase the resilience of organisations, particularly in terms of 'volunteer capital'. It is interesting to note that this influence is to be found in most of the areas identified as risk factors for organisations. It is, therefore, important for organisations to review and plan for the future involvement and development of volunteering because of this significant contribution from volunteers.

Having explored my model in practice, I now plan to further develop my revised theoretical model and my organisational risk factors to provide a tool to support organisations in assessing their strengths and vulnerabilities in relation to the sustainability elements of the volunteering contribution to their organisation. This would support and encourage more robust future planning and flexibility in adapting to the changing volunteering environment.

Data has shown that my theoretical model relates well to practice. It has been tested in hospices of different sizes, in adult, children's and hospices with both types of service and also in England and Scotland. In Scotland, 75% of hospices took part in the study and therefore it is likely that my model has wide

applicability here. Whilst there was a considerably smaller percentage of hospices in England, I believe that because of the variety of hospice types and sizes and respondents, the model may have wider significance and is likely to be particularly relevant to voluntary sector service delivery organisations. It is important, therefore, that further research is undertaken to explore the applicability of the model in wider range of organisations beyond hospices.

5.2 Conclusion and Recommendations

I set out to test the applicability of my theoretical model to explore the relationship between volunteering and the future sustainability of UK independent hospices and to understand how volunteering was understood in UK independent hospices by trustees, senior staff and volunteers. Whilst only a small percentage of hospices took part, the study generated a rich and varied source of data. It is clear that volunteers are considered as an integral part of the hospice team, which is somewhat at odds with previous research findings. This may suggest a maturing attitude towards hospice volunteering. However, further study with other hospices and staff groups is needed before this could be assumed. Those hospices which took part have identified a clear dependence on volunteering for service delivery, quality and range of services and the de-medicalisation of care, enabling a personal and holistic approach to care.

The role and influence of volunteering also changes throughout the different stages of organisational development, developing a particular ethos and culture

as a result. There is a need for the voluntary dimension of hospice organisations to be more widely recognised by policy makers, the statutory and private sectors and the general public as a unique element of holistic hospice care which distinguishes hospices from other health service providers. Volunteers enable hospices to be strongly integrated to local communities and have a key role to play in further developing this aspect, including a role in educating the public on work of hospices today. Volunteers have great potential to reduce the taboos, which surround, death, dying and bereavement and with the right training and support could further build capacity within communities to care and support the dying and bereaved. This requires openness to the new possibilities that volunteers can bring to hospices and this study suggests that there is willingness on the part of senior staff, trustees and volunteers to embrace this. This is very significant as it is trustees and senior staff who are often the gatekeepers to volunteering in organisations and who set the tone and direction of the management approach and the boundaries of volunteering activities. However, any development must also embrace and nurture the essence and uniqueness of volunteers. Further research is required, however, to understand why volunteers see their purpose in hospices so differently from senior staff and trustees. It is not clear whether this comes from an acceptable difference in perception, the messages given to or understood by volunteers or a disempowered volunteer workforce as a result of a limiting approach to volunteer management. Volunteers may indeed feel valued and motivated that their contribution enables hospices to be cost-effective, but it would be unwise to make any assumptions why volunteers see their involvement differently without further exploration and evidence.

I would suggest, however, that for volunteering to be an effective and empowered component of an organisation, the prime motivation for involving volunteers should not be reducing costs. For the volunteering relationship with the organisation to be successful, the expectations of both parties must be met. The focus must, therefore, be on the diversity which volunteers bring, and the skills and experience with which they enhance and develop services. There must also be clarity about their role within the organisational structure and workforce. This approach is likely to be successful in meeting the diverse needs of both the organisation and volunteers. If hospice volunteering is to develop and thrive in the future volunteers must be seen as equal partners in the development and delivery of care. There must also be recognition of the strategic significance of volunteers and the role they play in helping to achieve organisational strategy. Volunteering, therefore, need to be fully recognised as a strategic asset and considered in the same way as other key strategic areas.

Hospices, however, must compete to attract and retain the volunteers of the future. There will be competition with other organisations and with the many opportunities which people have to spend their leisure time. Volunteering trends fluctuate and it is not clear whether there will be a sufficient flow of people wishing to volunteer to meet the ever-increasing demand from organisations charged with doing more with less. Given the strong link between volunteering and hospice sustainability or, in some cases, continued existence, hospices must consider the sustainability of their voluntary service and identify the external factors, which may threaten or enhance. The lack of understanding of the role of volunteers in governance must be also addressed in this context if

effective governance is to be sustained in the changing landscape of hospice care. Changing trends in society and in volunteer expectations may also affect trustees in the future and thus threaten the governance structures of organisations. Organisations must be able to respond strategically to the rapidly changing policy, societal, demographic and economic landscapes. Strong governance is, therefore, essential to ensure sustainability and future success. Clearly, therefore, there needs to be effective and inclusive strategic and organisational planning for volunteering as a significant part of the hospice workforce and an approach to volunteer management which will both empower volunteers to use their skills for maximum benefit and meet the changing expectations of the volunteers of the future. Volunteering opportunities must remain attractive, fulfilling and rewarding to prospective volunteers at all levels of the organisation. Hospices must take the recruiting and nurturing of volunteers as seriously as they do the stewardship of donors and funders.

My model has, I believe, a useful application to voluntary organisations and has been shown to work for independent hospices of all types. In its present form, it can provide a useful indicator of the areas that hospices should monitor as part of strategic and on-going planning to ensure that the significance of volunteers is not overlooked. It provides a means of considering areas which impact on volunteering that might pose a risk to hospice sustainability and allows for a change in approach to mitigate this. Additionally, the theoretical model can be adapted and used for other areas of sustainability such as fundraising and staffing. For example, where my model currently shows external influences relating to volunteering and volunteering influences, these areas could be

replaced by external influences related to fundraising and fundraising influences.

My research question was: “What is the relationship between volunteering and the future sustainability of UK independent hospices?” I believe that findings from this study have answered this question. There is clear evidence from those hospices which took part that there is an inextricable link between volunteering and the four organisational sustainability factors identified in my model which influence the ability of these hospices to continue to deliver and develop services in the future. There was also evidence to suggest that volunteering had an influence beyond just these four organisational sustainability factors and had some influence on each of the eight areas. Volunteers have a complex relationship with hospices as their involvement strongly influences organisations at many different levels. Hospices must, therefore, recognise and nurture this symbiotic relationship if they are to remain sustainable in the changing landscape that is the future of palliative care.

5. 3 Limitations of the study

One limitation of this study is the small number of hospices which took part and therefore caution must be exercised in generalising findings. This research used a survey method as the only method of data collection. However, source triangulation was used to strengthen the validity of the data. Regional triangulation was also used as was triangulation between different hospice types, again to reduce bias and strengthen the validity of the findings. I also

triangulated the data from the Likert scale questions against the information from the free text questions. The use of a questionnaire gives respondents anonymity, which may permit them to be more open and honest in their answers. It also allows respondents to opt out of answering certain questions, which can be both strength and a limitation. There is also a risk with questionnaires that whilst they may seem straightforward to the researcher, they may have been open to misinterpretation by respondents. I therefore piloted the questionnaire before sending to respondents. This allowed any necessary changes to be made before distribution.

On reviewing the structure and content of the questionnaire, I would make some changes if I were to undertake a similar study again. I would ask for the region where the hospice is based to allow me additionally to interrogate data by region. Rather than give groupings for hospice bed, staff and volunteer numbers, I would ask for actual numbers. This would allow me to undertake closer analysis of this data, rather than assuming a median number for each area. I would have reworded questions to enable these to be asked across all groups to increase opportunities for comparison. I would also plan to use follow up interviews in future to allow me to further explore data from questionnaires.

5.4 Implications for policy, practice and future research

As UK hospices confront significant challenges in the face of: a difficult economic environment; a change in the approach to statutory funding (England and Wales); and a predicted increase in patient numbers; this study into the

relationship between volunteering and the future hospice sustainability of UK independent hospices comes at an opportune time. My research has provided new evidence and insights, which may change the way in which hospices understand and approach volunteering. This study has implications for other similarly structured voluntary organisations in the UK and beyond.

This study has implications for future policy and practice and has identified new areas for research. Policy makers, those involved in commissioning services or providing statutory funding must understand the vital role which volunteering plays in the sustainability of UK independent hospices as key providers of care. This would result in informed policy and commissioning of services which is less likely to have unintended consequences for volunteering. Hospices must also take their dependence on volunteers seriously. By considering volunteering as a strategic resource, monitoring external trends and influences, they will be in a stronger position to embrace new approaches to the planning for, and involvement of volunteers in creative and empowering roles. In turn, new approaches to volunteering would be able not only to meet the changing needs of patients but also the expectations of the volunteers of the future. Given the dependence of hospice sustainability on volunteers it is important that the future of this key resource is not left to chance. I believe this study has the ability to influence thinking about organisational strategy and its approach to volunteering. My study has the potential to encourage hospices to embrace new approaches to management which will enable volunteer skills to be used for maximum effectiveness and support the development of new roles for volunteers in care, capacity building and public education. The development of

my theoretical model which can also be used as an assessment tool also supports hospices to identify areas of strength and address any potential risks to sustainability through flexible planning, review and development.

This study has identified new areas for research in volunteering which include:

- Further exploration of my theoretical model as a tool to assess the value to other organisational settings, including those outwith the UK.
- Further research to explore why volunteers understand their involvement in hospices differently to senior staff and trustees.
- Research with the wider hospice team into attitudes to volunteers as part of the professional team.

As there is also a clear indication that hospices wish to develop more care focused roles for volunteers it would be valuable to identify enablers and barriers to the development of volunteering in this area.

5.5 New knowledge and significance of the study

This study was initially inspired by my professional knowledge, experience and understanding of volunteer involvement in hospices in the UK. Whilst the literature review identified a number of research papers on volunteering and palliative care, there were no studies which explored the strategic importance of volunteering in hospices, how well volunteering was understood in hospices or the relationship between volunteering and hospice sustainability. Indeed, there was little empirical evidence around the sustainability of hospices as

organisations. This study demonstrates for the first time the strategic importance of volunteering to hospices and the subsequent need to consider volunteering in the same way as other strategic assets and its place within the organisational structure. There is now new information to suggest that hospices depend heavily on volunteering in a range of key areas and in a small number of cases organisations may not be viable without this input. There is also clear commitment to the development of volunteering in care focussed roles which would indicate a change of thinking about the role of volunteers in hospices.

Interestingly, this study provides information to add to the hospice community engagement agenda. Findings suggest that volunteers have an important role to play in reducing taboos around hospice care, and death, dying and bereavement. It indicates that there is capacity to develop this role further in the future with appropriate training and support.

Whilst this research focussed solely on independent hospices in Scotland and England, there may be implications for similarly structured organisations in the UK and internationally.

My research has also brought new insights about the changing role and influence of volunteers at different stages in the development of the hospice organisation and the subsequent influence on culture and ethos. My Theoretical Model of Organisational Sustainability also adds to existing knowledge and makes an original contribution to the field of palliative care by identifying a number of organisational sustainability factors and a range of

external, internal and volunteering influences which impact on these. This has been explored in practice and has been found to be applicable to independent hospice organisations. Both the Theoretical Model and the identification of a number of organisational risk factors could be used to help hospices understand their areas of strength and areas for development in relation to volunteering as a strategic asset. My model could also be adapted for use in exploring the sustainability of a number of other strategic areas, for example, workforce planning and income generation. Contrary to previous research, my study has identified a possible shift in hospice attitudes towards volunteering, now perceiving volunteers as a valued and integral part of the professional team and recognising the reliance of the organisation on this resource.

My research has also highlighted a need for a more inclusive and organised approach to the strategic and operational planning for volunteer involvement as a significant part of the workforce. As far as I am aware, this study is the first to identify how differently volunteers understand their role in hospices compared to the perceptions of senior staff and trustees. This is an important finding and brings new considerations to those involving volunteers in their attempt to ensuring that volunteer expectations are matched with organisational need.

I intend to disseminate the findings from this study at national and international conferences and through publication in peer reviewed journals. To date I have presented the literature review as an oral presentation at a large international palliative care conference in Montreal in October 2012. In addition I have

presented a poster about the full study at a second international palliative care conference in Prague in May 2013. I have also been invited to speak about the findings from my study at a UK Volunteer Manager's Conference in Birmingham in November 2013 and have submitted an abstract to an international conference in the UK in October 2013. Additionally, I have been invited to submit a paper to two peer reviewed palliative care journals.

I am excited by the new knowledge generated from my research and the potential to inform further research and approaches to volunteering in hospices in the UK and beyond.

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Appendix 1

Summary of Literature Reviewed

Ref Number	First Author/Year	Title	Country	Document Type
1	Addington-Hall J. M., & Karlsen, S. (2005a)	A national survey of health professionals and volunteers working in voluntary hospices in the UK. I. Attitudes to current issues affecting hospices and palliative care.	UK	Research Paper
2	Addington-Hall J. M., & Karlsen,S. (2005b)	A national survey of health professionals and volunteers working in voluntary hospices in the UK. II. Staff and volunteers' experiences of working in hospices	UK	Research Paper
3	Andersson, B., & Ohlen, J. (2005) Being a hospice volunteer.	Being a hospice volunteer	Sweden	Research Paper
4	Audit Scotland (2008)	Review of palliative care services in Scotland.	Scotland	Policy Document
5	Barron, A. (2008)	Sharing Good Practice; The Management of Hospice Volunteering.	UK	Research Paper
6	Burbeck, R., Low, J., Sampson, E.L., Scott, R., Bravery, R. &, Candy, B. (2013)	Volunteer activity in specialist paediatric palliative care: a national survey.	UK	Research Paper
7	Cabinet Office (2010)	Building the Big Society	UK	Government Document
8	Cabinet Office (2011)	Big Society Overview	UK	Government Document
9	Cabinet Office (2013)	Community Life Survey	UK	Government Document
10	Calanzani, N., Higginson, I.J., & Gomes, B. (2013)	Current and future needs for hospice care:an evidence-based report	UK	Research Paper
11	Clark, D. (1998).	Originating a movement: Cicely Saunders and the development of St Christopher's Hospice, 1957-1967	UK	Discursive Paper

12	Clark, D. (1999)	Cradled to the Grave? Terminal Care in United Kingdom	UK	Discursive Paper
13	Clark, D. Small, N., Wright, M., Winslow, M., & Hughes, N. (2005)	A Bit Of Heaven For The Few? An Oral History Of The Modern Hospice Movement In The United Kindgom	UK	Book
14	Claxton-Oldfield, S., Jeffries, J., Fawcett, C., Wasylkiw,L., & Claxton-Oldfield, J. (2004)	Palliative Care Volunteers: Why do they do it?	Canada	Research Paper
15	Commission on the Future of Volunteering (2008)	Report Of The Commission On The Future Of Volunteering And Manifesto For Change.	UK	Report
16	Corner, J., Dunlop,R., (1997) in Clark, D., Hockley, J., & Ahmedzai, S.	New Approaches to Care In New Themes in Palliative Care.	UK	Book Chapter
17	Craft, A., & Killen, S., (2007) Department of Health. London.	Palliative Care Services for Children and Young People in England	England	Government Document
18	Cresswell, J. (2003)	Research Design; Qualitative, Quantitative and Mixed Methods Approaches.	UK	Book
19	Davis-Smith, J. (2004)	Volunteering in UK hospices: looking to the future	UK	Research Paper
20	Davis-Smith, J. (2006) in J. Davis-Smith, J., & M. Locke. (Eds.)	Beyond Sccial Capital: What Next For Voluntary Action Research?	UK	Book Chapter
21	Department of Health (2008)	Better Care: Better Lives	England	Government Document
22	Department of Health (2008)	End of Life Care Strategy	England	Government Document
23	Department of Health Social Services and Public Safety (2009)	Palliative and End of Life Strategy for Northern Ireland	Northern Ireland	Government Document
24	Dixon, N. (2000)	The Organisational Learning Cycle: How We Learn Collectively.		Book
25	Doyle, D. E. (Ed.) (2002)	Volunteers In Hospice And Palliative Care - A Handbook For Volunteer Service Managers.	International	Book

26	duBoulay, S. (2007)	Cicely Saunders The Founder of the Modern Hospice Movement	UK	Book
27	Dubin, R (1978)	Theory Building	USA	Book
28	Devaney, C., Bradley, S., & Together for Short Lives (2012)	Count me in: Children's hospice provision 2011/12.	UK	Research Paper
29	Dyer, P. (2008)	The Good Trustee Guide	UK	Book
30	Evans, E., & Saxton, J. (2005)	The 21st Century Volunteer. London	UK	Discursive Paper
31	Faulkner, M. & Davies, S. (2005)	Social support in the healthcare setting: the role of volunteers.	UK	Research Paper
32	Fisher, D., Rooke, D., & Torbert, B. (2003)	Personal And Organisational Transformations Through Action Enquiry	UK	Book
33	Gaskin, K. (2003)	The economics of hospice volunteering	UK	Research Paper
34	Gaskin, K. (2003)	A Choice Blend: What volunteers want from organisation and management	UK	Research Paper
35	Gay, P. (2001)	Bright Future: Developing Volunteer Management	UK	Research Paper
36	Guirguis-Younger M., (2008)	Narrative Accounts of Volunteers in Palliative Care Settings	USA	Discursive Paper
37	Guirguis-Younger, M., Kelley, M.,& McKee, M (2005).	Professionalisation of hospice volunteer practices: what are the implications?	USA	Research Paper
38	Hart, C. (a)	Doing a Literature Review	UK	Book
39	Hawkins, S., & Restall, M. (2006)	Volunteers Accross the NHS - improving the patient experience and creating a patient led service	UK	Research Paper
40	Help theHospices (2005)	Trustee Governance Pack	UK	Booklet
41	Help the Hospices (2006)	Volunteer Value; A pilot survey in UK hospices	UK	Research Paper
42	Help the Hospices (2006b)	Governance Matters: Charity Commission review visits to hospices (2001-2006)	UK	Research Paper

43	Help the Hospices (2011)	Help The Hospices Membership. The Benefits Of Being A member	UK	Booklet
44	Help the Hospices (2012a)	Directory of Hospice and Palliative Care	UK	Book
45	Help the Hospices (2012b)	Volunteers: Vital To The Future Of Hospice Care. A Working Paper Of The Commission Into The Future Of Hospice Care.	UK	Report
46	Hill, M. (2011)	Volunteering and the recession	UK	Research Paper
47	Hoad, P. (1991)	Volunteers in the Independent Hospice Movement	UK	Research Paper
48	Howlett, S., (2009) in R. Scott, R., S. Howlett, S., & D. Doyle, D. (Eds)	Setting the Scene: the landscape of volunteering. in Volunteers in Hospice and Palliative Care. A Resource for Voluntary Services Managers.	International	Book Chapter
49	Hughes-Hallet, T., Craft, A., & Davies, C. (2011)	Palliative Care Funding Review, Finding the Right Support for Everyone	England	Report
50	Hustinx, L., Cnaan,R., & Handy, F. (2010)	Navigating Theories of Volunteering: A Hybrid Map for a complex phenomenon	International	Discursive Paper
51	James, N., & Field, D. (1992)	The routinization of hospice: charisma and bureacratization.	UK	Discursive paper
52	Kilduff, M. (2006)	Editor's Comments:publishing Theory	USA	Discursive paper
53	Kumar, S., & Matthews, N. (2005)	Neighbourhood Network in Palliative Care	India	Discursive paper
54	Leadbetter, C., & Garber,J. (2010)	Dying for a Change	UK	Research Paper
55	McCurley, S., & Lynch, R.(1998)	Essential Volunteer Management.	USA	Book
56	Mintzberg, H., Ahlstrand, B., & Lampel, J. (1998)	Strategy Safari	USA	Book
57	Morris, S., Wilmot, A., Hill, M., Ockenden, N., & Payne, S. (2013).	A narrative literature review of the contribution of volunteers in end-of-life care services.	International	Research Paper

58	National Audit Office (2008)	End of Life Care	England	Government Document
59	Naylor, C., Mundle, C., Weaks, L., & Buck, D. (2013)	Volunteering in Health and Care. Securing a sustainable future.	UK	Research Paper
60	Pastor, D. (2010)	Exploring Attitudes to Volunteering at Hospices for Children and Young Adults.	UK	Research Paper: Thesis
61	Rochester, C. (2006). London	Making Sense of Volunteering	UK	Discursive Paper -Report
62	Rochester, C., Ellis Paine, A., & Howlett, S. with Zimmeck,M. (2010)	Volunteering and Society in 21st Century	UK	Book
63	Sallnow, L. (2010)	Conceptualisation of Volunteering in Palliative Care	UK	Research Paper: Thesis
64	Scott, R. (2006a).	Volunteers in a Children's Hospice A study of the impact of volunteers in Rachel House Children's Hospice	UK	Research Paper
65	Scott, R. (2006b)	Volunteers: Ministering or Meddling: A study of UK Children's hospices experinces of volunteers.	UK	Unpublished Research Paper
66	Scott, R. (2007)	Volunteer Value: A Toolkit For Measuring The Economic Value Of Hospice Volunteers.	UK	Booklet
67	Scott, R. (2009) in R. Scott, S. Howlett, & D. Doyle, (Eds.)	Volunteers In A Children's Hospice. In Volunteers In Hospice And Palliative Care. A Resource For Voluntary Services Managers.	International	Book Chapter
68	Scott, R. Howlett, S., & Doyle, D. (Eds.) (2009)	Volunteers In Hospice And Palliative Care - A Resource For Voluntary Services Managers	UK	Book
69	Scottish Children and Young People's Palliative Care Executive Group (SCYPPEx)	A Framework for the Delivery of Palliative Care for Children and Young People in Scotland. Group (SCYPPEx).	Scotland	Government Document

	(2013)			
70	Scottish Partnership for Palliative Care (2006)	Joined Up Thinking Joined Up Care.... Report Of The Scottish Partnership For Palliative Care, Big Lottery Fund Project.	Scotland	Report
71	Scottish Government (2001)	Active Communities Newsletter	Scotland	Government Document
72	Scottish Executive (2004)	Volunteering Strategy	Scotland	Government Document
73	Scottish Government (2007)	Better Health Better Care	Scotland	Government Document
74	Scottish Government (2008)	Living and Dying Well	Scotland	Government Document
75	Scottish Government (2008)	Refreshed Strategy for Volunteering in the NHS in Scotland	Scotland	Government Document
76	Scottish Government (2010)	Scottish Household Survey	Scotland	Government Document
77	Scottish Partnership for Palliative Care (2007)	Palliative And End Of Life Care In Scotland: The Case For A Cohesive Approach	Scotland	Policy Document
78	Sugar, V. (2008)	Palliative Care Planning Group Wales: Report to the Minister for Health and Social Services	Wales	Government Document
79	Turner, M. , & Payne, S. (2008)	Uncovering the hidden volunteers in palliative care: a survey of hospice trustees in the United Kingdom	UK	Research Paper
80	Turner, M., & Payne, S. (2009)	Governance in changing times: the experiences of hospice trustees in the United Kingdom.	UK	Research Paper
81	Volunteer Development Scotland (2013)	No title (accessed for statistical information)	Scotland	Web page
82	Wallace M., & Wray, A. (2006)	Critical Reading and Writing for Postgraduates	UK	Book
82	Welsh Government (2013).	Together For Health – Delivering End Of Life Care. A Delivery Plan Up To 2016 For NHS Wales And Its Partners.	Wales	Government Paper

84	Wilson, D. M., Justice, C., Thomas, R., Sheps, S., MacAdam, M., & Brown, M. (2005)	End-of-life care volunteers: a systematic review of the literature	Canada	Research Paper
85	Wilson, J. (2000)	Volunteering	USA	Discursive Paper
86	Wise, D. (2001)	Would the payment of market rates for non-executive directors strenghthen charity governance?	UK	Discursive Paper
87	World Health Organisation (1998).	(No title – accessed for definition)	International	Web Page
88	Worswick, J. 1993	A House Called Helen, The Development Of Hospice Care For Children.	UK	Book
89	Zimmeck, M. (2001)	The right stuff: New ways of thinking about volunteers	UK	Research Paper

APPENDIX 2

PARTICIPANT INFORMATION SHEET

PROJECT TITLE: Strategic Asset or Optional Extra? -
The impact of volunteers on hospice sustainability

INVITATION TO TAKE PART IN A RESEARCH STUDY

You are being invited to take part in a research study, which is exploring the impact which volunteers have on UK independent hospices and the relationship between volunteering and the sustainability of the organisation. I am a Doctoral student at the University of Dundee and am also employed in a children's hospice. My research is being supervised by Professor Divya Jindal-Snape and Dr Gaye Manwaring.

If you agree to take part in this study you will be asked to complete an online questionnaire and take part in a telephone interview.

PURPOSE OF THE RESEARCH STUDY

This study will explore the link between volunteering and hospice sustainability in the UK by:

- Exploring how volunteering is understood UK hospice senior staff, volunteers and trustees
- Considering the influence of volunteers on four key UK hospice areas: governance; care; hospice economy and finance; and involvement with local communities
- Develop indicators for hospices to assess the impact of volunteering on their sustainability to inform the development of future strategy

TIME COMMITMENT
The study will require approximately 15-20 minutes to complete the questionnaire. If you agree to take part in follow up semi-structured interviews, these will take no more than 1 hour.

TERMINATION OF PARTICIPATION
You may decide to stop being a part of the research study at any time without explanation. You will not be disadvantaged in any way should you choose to do so.

RISKS
There are no known risks for you in this study.

COST, REIMBURSEMENT AND COMPENSATION
Your participation in this study is voluntary.

CONFIDENTIALITY/ANONYMITY
The data we collect do not contain any personal information about you except your role and the hospice in which you work/volunteer. Questionnaires are all anonymous. Interviews will be audio-recorded and recordings will be destroyed once the transcript of the recording has been finalised. All data from the interviews will be made anonymous in the transcripts and in the research report by the use of pseudonyms. Confidentiality is assured throughout and the research report and any publications and presentations will be anonymised to ensure that no individual participant or hospice is identifiable. Results will be published in peer-reviewed journals and at conferences.

FOR FURTHER INFORMATION ABOUT THIS RESEARCH STUDY

Ros Scott will be glad to answer your questions about this study at any time. If you want to find out about the final results of this study, you should contact Ros Scott.

You may contact her at rzscott@dundee.ac.uk or by telephone :0131 444 4005

Ros Scott
Professional Doctorate Student
University of Dundee
School of Education, Social Work and Community Education
Nethergate
Dundee DD1 4HN

The University Research Ethics Committee of the University of Dundee has reviewed and approved this research study.

APPENDIX 3

Reply Reply All Forward Chat

Fw: UREC 12104 - approved

Ros Scott [rosc.scott@btinternet.com]

18 November 2012 17:29

To: Rosalind Scott

----- Forwarded Message -----
From: Astrid Schloerscheidt <A.Schloerscheidt@dundee.ac.uk>
To: Ros Scott <rosc.scott@btinternet.com>
Cc: Astrid Schloerscheidt <A.Schloerscheidt@dundee.ac.uk>; Elizabeth Evans <e.evans@dundee.ac.uk>
Sent: Wednesday, 7 November 2012, 14:45
Subject: UREC 12104 - approved

Dear Ros,

your application is now approved.

Best of luck with your research.

Astrid

Dr. Astrid Schloerscheidt
Chair, University of Dundee Ethics Committee

The University of Dundee is a registered Scottish Charity, No: SC015096

On 4 Nov 2012, at 12:55, Ros Scott wrote:

> Dear Astrid
>
> Many thanks for your email. I have now updated the study protocol as requested and this is now attached.
>
> Thank you gain for your help and guidance.
>
> Kind regards
>
> Ros
>
> **From:** Astrid Schloerscheidt <A.Schloerscheidt@dundee.ac.uk>
> **To:** Ros Scott <rosc.scott@btinternet.com>
> **Cc:** Astrid Schloerscheidt <A.Schloerscheidt@dundee.ac.uk>
> **Sent:** Thursday, 25 October 2012, 12:16

APPENDIX 4

COPY OF SURVEY AS LAID OUT in BRISTOL ONLINE SURVEY

Questionnaire for Senior Staff

Strategic Asset or Optional Asset

Welcome

Welcome to the survey. This survey aims to explore the impact which volunteers have on UK independent hospices and the relationship between volunteering and the sustainability of the organisation.

The survey is completed anonymously, can be saved part way through and takes around 20 minutes to complete. All data collected in this study will be held anonymously and securely. No personal data is asked for or retained. Cookies, personal data stored by your Web browser, are not used in this survey.

Please note that by completing this questionnaire you indicate that you give your consent to taking part in the questionnaire part of this research study.

As part of the study you are also invited to take part in a telephone interview. If you would like to give consent to do this, please complete the contact detail section at the end of the questionnaire with your name and telephone number or email so that this may be followed up. Your details will be noted separately and deleted from the questionnaire before it is analysed to ensure anonymity.

Note that once you have clicked on the CONTINUE button at the bottom of each page you cannot return to review or amend that page.

Section 1: About the hospice

This section asks for information about the hospice where you work.

1	What is the name of the hospice?
2	Who does the hospice care for
	Adults only Children only Children and young adults Both adults and children
3	What services does the hospice provide?
	Inpatient Day-care Home care
	Other *(please specify)*
4	If inpatient - how many beds does your hospice have?
	1-5 5-10 10-15 15-20 over 20
	Other *(please specify)*
5	What is your job title *(optional)*
6	How many staff and volunteers are there?
	Staff 1-50 50-100 100-150 150-200 over 200
	Other *(please specify)*
	Volunteers 1-50 50-100 100-200 200-400 400-600 600-800 800-1000
	Other *(please specify)*
7	Who is manages volunteers in the organisation? (*select all that apply*)
	Volunteer Manager Volunteer Co-ordinator Clinical member of staff Non clinical member of staff Fundraising Manager Retail Manager

Section 2: Trustees and volunteering

This section includes a range of statements about trustees and volunteering. Please tick only **one** box which is closest to your opinion for each statement.

Question 7		**Strongly Agree**	**Agree**	**Disagree**	**Strongly disagree**	**N/A**
a	Staff understand that the hospice trustees are volunteers					
b	Staff understand the role of the trustees					
c	The trustees seek the views of the staff					
d	The staff have opportunities to meet and talk with the trustees					
e	Staff contribute to the development of the strategic plan					
f	Volunteers contribute to the development of the strategic plan					
g	Volunteering is explicitly mentioned in the strategic plan					
h	The impact of volunteering in the hospice is measured					
i	Volunteering increases the ability of the hospice to provide services					
j	The hospice states publicly why volunteers are involved					

Section 3: The volunteer contribution to the hospice

This section includes a range of statements about the role of volunteers and how they contribute to the hospice. Please tick only **one** box which is closest to your opinion for each statement.

Question 8		**Strongly Agree**	**Agree**	**Disagree**	**Strongly disagree**	**N/A**
a	Volunteers are recognised as an integral part off the staff team					
b	There is a plan specifically relating to volunteering					
c	We know how many volunteers we will need to deliver our service next year					
d	We consider how volunteers might contribute when we develop new projects					
e	Volunteers bring skills which add to those of paid staff					
f	Volunteers bring a different approach to that of paid staff					
g	Volunteers are important to patient care					
h	Volunteers are important to the support given to families					
i	Volunteers contribute to the financial success of this hospice					
j	Volunteers help to make our services sustainable					
k	Volunteers are important in raising funds					
l	There is a budget for volunteering					
m	The costs associated with volunteering are calculated					
n	The economic impact of volunteering is calculated					
o	Economic impact is used to inform future planning					
p	The hospice would not be able to provide all the services it does without volunteers					

Section 4: Public and community involvement.

This section includes a range of statements about the volunteering and the local community. Please tick only **one** box which is closest to your opinion for each statement.

Question 9		**Strongly Agree**	**Agree**	**Disagree**	**Strongly disagree**	**N/A**
a	Volunteers come from communities local to the hospice					
b	Volunteers help to make the hospice part of the community					
c	Volunteers raise awareness in the local community of the work of the hospice					
d	Volunteers help to reduce the fear which surrounds hospices					
e	Volunteers make it easier for people to use the services of the hospice					
f	Volunteers help people in the community to talk about death and dying					
g	Volunteers increase people's ability to support people in the community facing the end of life					
h	Volunteers bring the views of the community to the hospice					
i	Volunteers have a lot to offer in helping the hospice to become more involved with the communities					

10.	Why does the hospice involve volunteers?
11.	What else could volunteers do to support the hospice?

THANK YOU FOR TAKING TIME TO COMPLETE THIS QUESTIONNAIRE

I would like to take part in the interview – here are my contact details._____

APPENDIX 5
COPY OF SURVEY AS LAID OUT in BRISTOL ONLINE SURVEY

Questionnaire for trustees

Strategic Asset or Optional Asset

Welcome

Welcome to the survey. This survey aims to explore the impact which volunteers have on UK independent hospices and the relationship between volunteering and the sustainability of the organisation.

The survey is completed anonymously, can be saved part way through and takes around 20 minutes to complete. All data collected in this study will be held anonymously an securely. No personal data is asked for or retained. Cookies, personal data stored by your Web browser, are not used in this survey.

Please note that by completing this questionnaire you indicate that you give your consent to taking part in the questionnaire part of this research study.

As part of the study you are also invited to take part in a telephone interview. If you would like to give consent to do this, please complete the contact detail section at the end of the questionnaire with your name and telephone number or email so that this may be followed up. Your details will be noted separately and deleted from the questionnaire before it is analysed to ensure anonymity.

Note that once you have clicked on the CONTINUE button at the bottom of each page you cannot return to review or amend that pag

Section 1: About the hospice

This section asks for information about the hospice where you work.

1	What is the name of the hospice?
2	Who does the hospice care for
	Adults only Children only Children and young adults Both adults and children
3	What services does the hospice provide?
	Inpatient Day-care Home care
	Other *(please specify)*
	If inpatient - how many beds does your hospice have?
	1-5 5-10 10-15 15-20 over 20
	Other *(please specify)*
4	What is your trustee role? (For example: finance, clinical, business, medical) *(optional)*
5	How many staff and volunteers are there?
	Staff 1-50 50-100 100-150 150-200 over 200
	Other *(please specify)*
	Volunteers 1-50 50-100 100-200 200-400 400-600 600-800 800-1000
	Other *(please specify)*
6	Who is manages volunteers in the organisation? (*select all that apply*)
	Volunteer Manager Volunteer Co-ordinator Clinical member of staff Non clinical member of staff Fundraising Manager Retail Manager

Section 2: Trustees and volunteering

This section includes a range of statements about trustees and volunteering. Please tick only **one** box which is closest to your opinion for each statement.

Question 7		**Strongly Agree**	**Agree**	**Disagree**	**Strongly disagree**	**N/A**
a	Volunteers in the organisation know that the trustees are also volunteers					
b	The trustees seek the views of volunteers					
c	The trustees seek the views of staff					
d	The volunteers have opportunities to meet and talk with the trustees					
e	The staff have opportunities to meet and talk with the trustees					
f	Volunteers contribute to the development of the strategic plan					
g	Staff contribute to the development of the strategic plan					
h	Volunteering is explicitly mentioned in the strategic plan					
i	The impact of volunteering in the hospice is measured					
j	Volunteering increases the ability of the hospice to provide services					
k	The hospice states publicly why volunteers are involved					

Section 3: The volunteer contribution to the hospice

This section includes a range of statements about the role of volunteers and how they contribute to the hospice. Please tick only **one** box which is closest to your opinion for each statement.

Question 8		**Strongly Agree**	**Agree**	**Disagree**	**Strongly disagree**	**N/A**
a	Volunteers are recognised as an integral part off the staff team					
b	Volunteers bring skills which add to those of paid staff					
c	Volunteers bring a different approach to that of paid staff					
d	Volunteers are important to patient care					
e	Volunteers are important to the support given to families					
f	Volunteers contribute to the financial success of this hospice					
g	The economic impact of volunteering is calculated					
h	Volunteers help to make our services sustainable					
i	Volunteers are important in raising funds					
j	The hospice would not be able to provide all the services it does without volunteers					

Section 4: Public and community involvement.

This section includes a range of statements about the volunteering and the local community. Please tick only **one** box which is closest to your opinion for each statement.

Question 9		**Strongly Agree**	**Agree**	**Disagree**	**Strongly disagree**	**N/A**
a	Trustees come from communities local to the hospice					
b	Volunteers help to make the hospice part of the community					
c	Volunteers raise awareness in the local community of the work of the hospice					
d	Volunteers help to reduce the fear which surrounds hospices					
e	Volunteers make it easier for people to use the services of the hospice					
f	Volunteers help people in the community to talk about death and dying					
g	Volunteers increase people's ability to support people in the community facing the end of life					
h	Volunteers bring the views of the community to the hospice					
i	Volunteers have a lot to offer in helping the hospice to become more involved with the communities					

10.	Why does the hospice involve volunteers?
11.	What else could volunteers do to support the hospice?

THANK YOU FOR TAKING TIME TO COMPLETE THIS QUESTIONNAIRE

I would like to take part in the interview – here are my contact details._____

APPENDIX 6
COPY OF SURVEY AS LAID OUT in BRISTOL ONLINE SURVEY

Questionnaire for volunteers

Strategic Asset or Optional Asset

Welcome

Welcome to the survey. This survey aims to explore the impact which volunteers have on UK independent hospices and the relationship between volunteering and the sustainability of the organisation.

The survey is completed anonymously, can be saved part way through and takes around 15 minutes to complete. All data collected in this study will be held anonymously an securely. No personal data is asked for or retained. Cookies, personal data stored by your Web browser, are not used in this survey.

Please note that by completing this questionnaire you indicate that you give your consent to taking part in the questionnaire part of this research study.

As part of the study you are also invited to take part in a telephone interview. If you would like to give consent to do this, please complete the contact detail section with your name and telephone number or email address at the end of the questionnaire so that this may be followed up. Your details will be noted separately and deleted from the questionnaire before it is analysed to ensure anonymity.

Note that once you have clicked on the CONTINUE button at the bottom of each page you cannot return to review or amend that page.

Section 1: About the hospice

This section asks for information about the hospice where you volunteer.

Section 1 - About your hospice	
1	Please give the name of the hospice
2	Who does the hospice care for? *(select all that apply)*
	Adults only Children and young adults Children only Both adults and children
3	What services does the hospice provide? *(select all that apply)*
	Inpatient Day-care Home care
	Other *(please specify)*
4	If the hospice cares for inpatients inpatient - how many beds does it have?
	1-5 5-10 10-15 15-20 20-30
	Other *(please specify)*
5	What is your volunteer role? *(optional)*
6	Who is responsible for all volunteers in the organisation? (*select all that apply)*
	Volunteer Manager/Co-ordinator Clinical member of staff Non clinical member of staff Fundraising Manager Shop Manager
	Other *(please specify)*

Section 2: Trustees and volunteering

This section includes a range of statements about trustees and volunteering. Please tick only **one** box which is closest to your opinion for each statement.

Question 7		**Strongly Agree**	**Agree**	**Disagree**	**Strongly disagree**	**N/A**
a	I know that the hospice trustees are volunteers					
b	I understand understand the role of the trustees					
c	The trustees seek the views of the volunteers					
d	The volunteers have opportunities to meet and talk with the trustees					
e	Volunteering increases the ability of the hospice to provide services					
f	The hospice states publicly why volunteers are involved					

Section 3: The volunteer contribution to the hospice

This section includes a range of statements about the role of volunteers and how they contribute to the hospice. Please tick only **one** box which is closest to your opinion for each statement.

Question 8		**Strongly Agree**	**Agree**	**Disagree**	**Strongly disagree**	**N/A**
a	Volunteers are treated as an integral part off the staff team					
b	Volunteers bring skills which add to those of paid staff					
c	Volunteers bring a different approach to that of paid staff					
d	Volunteers are important to patient care					
e	Volunteers are important to the support given to families					
f	Volunteers contribute to the financial success of this hospice					
g	Volunteers help to make our services sustainable					
h	The costs associated with volunteering are calculated					
i	Volunteers are important in raising funds					
j	The hospice would not be able to provide all the services it does without volunteers					

Section 4: Public and community involvement.

This section includes a range of statements about the volunteering and the local community. Please tick only **one** box which is closest to your opinion for each statement.

Question 9		**Strongly Agree**	**Agree**	**Disagree**	**Strongly disagree**	**N/A**
a	Volunteers come from communities local to the hospice					
b	Volunteers help to make the hospice part of the community					
c	Volunteers raise awareness in the local community of the work of the hospice					
d	Volunteers help to reduce the fear which surrounds hospices					
e	Volunteers make it easier for people to use the services of the hospice					
f	Volunteers help people in the community to talk about death and dying					
g	Volunteers increase people's ability to support people in the community facing the end of life					
h	Volunteers bring the views of the community to the hospice					
i	Volunteers have a lot to offer in helping the hospice to become more involved with the communities					

10.	Why does the hospice involve volunteers?
11.	What else could volunteers do to support the hospice?

THANK YOU FOR TAKING TIME TO COMPLETE THIS QUESTIONNAIRE

I would like to take part in the interview – here are my contact details._____

APPENDIX 7

PROFESSIONAL DOCTORATE APEL CLAIM

PROFESSIONAL DOCTORATE APEL CLAIM

Rosalind Scott: Matriculation No: 030015787

Contents

APEL CLAIM Part 1

Rosalind Scott

Matriculation No: 030015787

Introduction

I was motivated to make my APEL claim for 2.5 modules of the Professional Doctorate because of my previous experience of practitioner research, writing and publication. I felt it would be a valuable learning experience to revisit past work, consider this critically, review my research journey and the knowledge which I had gained. This process was also valuable in identifying areas for development.

My background

Having trained and worked as a therapy radiographer, where I developed a passionate interest in palliative care, I moved into volunteer management in an adult hospice in 1991. From there I moved into a similar role in 1996 in Rachel House children's hospice, part of the Children's Hospice Association Scotland (CHAS) where I had the opportunity to develop a now significant voluntary service from small beginnings. The role grew from hospice volunteer co-ordinator to Head of Voluntary Services, a senior management position with responsibility for the CHAS voluntary service across Scotland. In 2007 I was appointed as Director of Organisational Development and currently have responsibility for Human Resources, Voluntary Services, Learning and Development, non-care organisational policy and change management.

My research journey

Whilst undertaking a Certificate in Volunteer Management, I undertook several small scale research projects. Seeing the benefits of these in terms of building both my own and my organisation's capacity, knowledge and understanding, it was also rewarding to see the benefits of changes to practice brought about by my studies. I became very excited by research and after the publication of a paper arising from a project exploring the issues of young volunteers in children's hospices, I decided to pursue a direction which would enable me to lean more about the theory and practice of research and develop my credibility as a researcher. I therefore embarked on an MSc in Advanced Professional Studies at Dundee University in 2004 during which I undertook a number of research projects which helped to develop practice, not only in my own organisation but also in the wider field of volunteering in palliative care.

My APEL Journey

I have learned a great deal from revisiting projects undertaken out with the MSc programme for this APEL claim. In reviewing these critically with fresh eyes, I have been able to identify my

shortcomings in terms of research planning and design, the lack of literature review before embarking on any enquiry and lack of consistency in referencing and writing skills. I also recognise the importance of effective preparation and planning for all stages of a research project and ensuring that a structured timetable with achievable timescales is set. I have come to understand the importance of a thorough and effective critical analysis of the literature and am looking forward to putting this learning into practice in the forthcoming modules. Through the work for this APEL, I have continued to develop my skills of critical analysis which will be helpful to me in the modules which follow.

I have also been able to chart the development of my skills and confidence in research. The culmination of this came in Part 1 "So what about us?" in which I had to give some basic training in qualitative research methods with my colleagues. This challenged me to revise and refresh my own knowledge and I very much enjoyed sharing my passion for research with others as we worked through the process together. I also very much enjoyed reflecting on the process of editing the book "Volunteers in Palliative Care" and my experience as a contributing author.

It is clear, however, that there are areas which I need to work on as I progress through my doctoral studies. These include: critical analysis of literature, development of literature search skills and handling of information, design and structure of research projects and the critical evaluation of numerical data.

Next stage

I look forward to the opportunity to address these issues throughout the doctorate modules which follow. Volunteering in palliative care is an under-researched area with much of the research focusing on volunteer motivations and management. Hospices are also very traditional in their approach to volunteering with formal and hierarchical structures in place. With an ever developing UK government focus on volunteering, changing demographics and volunteer expectations, it is my belief that we must change our volunteering models if the proud tradition of volunteer involvement in hospices is to remain sustainable in the future.

It is my intention therefore to explore the transferability to the UK of the model of neighbourhood networks in palliative care in Kerala in India. This community model is considered to be a health promotion model, maximizing the skills and expertise of local communities. Currently in the UK there is considerable discussion around engaging the public in discussions around death and dying and the development of hospices in their local communities. There is a tremendous opportunity, therefore, for research in this area to contribute to the development of volunteering models and of palliative care in the UK and I am really looking forward to exploring this area.

March 2010

Matrix showing the learning outcomes that have been met in the claims

SCQF Level 12 Learning Outcomes	Claim Part 1	Claim Part 2	Claim Part 3	Claim Part 4	Claim Part 5
Knowledge and Understanding					
A critical overview of a subject / discipline, including critical understanding of the principal theories, principles and concepts. **(KU 1)**	X	X	X	X	X
A critical, detailed and often leading knowledge and understanding of the forefront of one or more specialisms. **(KU 2)**	X	X	X	X	X
Knowledge and understanding that is generated through personal research or equivalent work which makes a significant contribution to the development of a subject or discipline **(KU 3)**	X	X	X	X	X
Practice: Applied knowledge and understanding					
Use a significant range of principal skills, techniques, practices and materials associated with a subject/discipline. **(P1)**	X	X	X	X	X
Use and enhance a range of complex skills, techniques, practices and materials at the forefront of one or more specialisms. **(P2)**	X	X	X	X	X
Apply a range of standard and specialised research/ equivalent instruments and techniques of enquiry. **(P3)**	X	X	X	X	X
Design and execute research, investigative or development projects to deal with new problems and issues **(P4)**	X	X	X		X
Demonstrate originality and creativity in the development and application of new knowledge, understanding and practices. **(P5)**	X	X	X	X	X
Practice in the context of new problems and circumstances.**(P6)**	X		X		X
Generic Cognitive Skills					
Apply a constant and integrated approach to critical analysis, evaluation and synthesis of	X	X	X	X	

new and complex ideas, information and issues. **(G1)**					
Identify, conceptualise and offer original and creative insights into new, complex and abstract ideas, information and issues. **(G2)**	X	X	X		X
Develop creative and original responses to problems and issues **(G3)**	X	X	X		X
Deal with very complex and/or new issues and make informed judgements in the absence of complete or inconsistent data/information. **(G4)**	X	X	X	X	X
Communication, ICT and numeracy skills					
Communicate at an appropriate level to a range of audiences and adapt communication to the context and purpose. **(C1)**	X	X	X	X	X
Communicate at the standard of published academic work and/or critical dialogue and review with peers and experts in other specialisms. **(C2)**	X	X	X	X	X
Use a range of software to support and enhance work at this level and specify software requirements to enhance work. **(C3)**	X	X	X	X	X
Critically evaluate numerical and graphical data. **(C4)**	X		X		
Autonomy, accountability and working with others					
Exercise a high level of autonomy and initiative in professional and equivalent activities. **(A1)**	X	X	X	X	X
Take full responsibility for won work and/significant responsibility for the work of others. **(A2)**	X	X	X	X	X
Demonstrate leadership and/or originality in tackling and solving problems and issues. **(A3)**	X	X	X	X	X
Work in ways which are reflective, self-critical and based on research evidence. **(A4)**	X	X	X	X	X
Deal with complex ethical and professional issues. **(A5)**	X	X	X	X	X
Make informed judgements on new and emerging issues not addressed by current professional and/or ethical codes or practices. **(A6)**	X	X	X		

APEL CLAIM Part 1 **Rosalind Scott**

Matriculation No: 030015787

Research Paper: So What About Us?

Contents

APEL CLAIM: Part 1 **Rosalind Scott**

Matriculation No: 030015787

Research Paper: "So What About Us?"

Introduction

The purpose of this APEL claim is to demonstrate that the research and publication evidenced in the research report "So What About Us?" (2008) (Appendix 1:1) was undertaken at doctoral level. This paper reports the work undertaken for the Children's Hospice Association Scotland in researching the needs and aspirations of young adults (aged 16 years and over) with palliative care needs and was carried out in order to inform and influence the development of services for this group.

Structure of Claim Document

This paper is structured under the five headings of the Scottish Curriculum and Qualifications Framework Level 12 doctoral level criteria (SCQF, 2003) (Appendix 1:2):

- Knowledge and Understanding
- Practice: Applied knowledge and understanding
- Generic Cognitive Skills
- Communication, ICT and numeracy skills
- Autonomy, accountability and working with others

Under each of the headings I will evidence the work undertaken for the project against the characteristic generic learning outcomes. As these are intended to give a general overview of learning outcomes, I will endeavour to match these as closely as possible, recognising however that not all evidence will match exactly.

In submitting evidence against the learning outcomes, I have used 5 different tables, one for each of the 5 headings outlined above. "So What about us?" is attached as Appendix 1:1 and the sections which are cited as evidence are highlighted in yellow. I have used

abbreviations for each learning outcome as outlined in each table to reference evidence in the report in Appendix 1:1.

In all sections I have set out to evidence the learning outcomes in relation to my critical understanding of the theories, thinking and knowledge at the forefront of the issues in the care of young adults with life-limiting conditions. I also evidence the use and development of skills, knowledge and understanding which resulted from my research and which I believe has implications for all organisations which care for life-limited young adults and therefore makes a significant contribution to developing our understanding of the unique issues which young adults with life limiting conditions face.

1. Knowledge and Understanding

The SCQF criteria under this heading requires demonstration of/ and or work with:

- A critical overview of a subject / discipline, including critical understanding of the principal theories, principles and concepts. KU 1

- A critical, detailed and often leading knowledge and understanding of the forefront of one or more specialisms. KU 2

- Knowledge and understanding that is generated through personal research or equivalent work which makes a significant contribution to the development of a subject or discipline. KU 3

Table 1: Evidence for Knowledge and Understanding

Learning Outcomes	Evidence
A critical overview of a subject / discipline, including critical understanding of the principal theories, principles and concepts. **(KU 1)**	Report Page 4 :'Introduction' highlighted text
	Report Page 4, 5 :'Context of research' highlighted text
	Report Page 6 highlighted text
	Report Page 8 highlighted text
A critical, detailed and often leading knowledge and understanding of the forefront of one or more specialisms. **(KU 2)**	Report Page 6 highlighted text
	Report Page 7 'Literature review' highlighted text
	Report Page 8 highlighted text
Knowledge and understanding that is generated through personal research or equivalent work which makes a significant contribution to the development of a subject or discipline **(KU 3)**	Report Page 7 Purpose of Research highlighted text
	Report Page 7 'Literature review' highlighted text
	Report Page 8 Paragraph 4, 5, 6,7 highlighted text
	Report Page 16, 17 Discussion of Findings
	Report Page 19 Conclusions and Recommendations
	This paper Section 6 'Outcomes and Impact'

2. Practice: Applied knowledge and understanding

The SCQF criteria under this heading require demonstration of the ability to:

- Use a significant range of principal skills, techniques, practices and materials associated with a subject/discipline. P1
- Use and enhance a range of complex skills, techniques, practices and materials at the forefront of one or more specialisms. P2
- Apply a range of standard and specialised research/ equivalent instruments and techniques of enquiry. P3
- Design and execute research, investigative or development projects to deal with new problems and issues P4

- Demonstrate originality and creativity in the development and application of new knowledge, understanding and practices. P5
- Practice in the context of new problems and circumstances P6

Table 2: Evidence for Practice: Applied knowledge and understanding

Learning Outcomes	Evidence
Use a significant range of principal skills, techniques, practices and materials associated with a subject/discipline. **(P1)**	Report Page 8,9 Methodology
	Report Page 9, Data Analysis
	Report Page 10,11 Sampling, Ethical Issues
Use and enhance a range of complex skills, techniques, practices and materials at the forefront of one or more specialisms. **(P2)**	Report Page 8,9 Methodology
	Report Page 9, Data Analysis
	Report Page 10, 11 Sampling, Ethical Issues
	This paper Reflections on Research
Apply a range of standard and specialised research/ equivalent instruments and techniques of enquiry. ***(*P3)**	Report Page 8,9 Methodology
	Report Page 9 Data Analysis
	Report Page 10, 11 Sampling, Ethical Issues
Design and execute research, investigative or development projects to deal with new problems and issues **(P4)**	Report Page 8,9 Methodology
	Report Page 9 Data Analysis
	Report Page 10 Sampling
Demonstrate originality and creativity in the development and application of new knowledge, understanding and practices. **(P5)**	Report Page 9 Methodology
Practice in the context of new problems and circumstances. **(P6)**	Report Page 9 Methodology
	This paper Section 6 'Outcomes and Impact'

3. Generic Cognitive Skills

The SCQF criteria under this heading require demonstration of the ability to:

- Apply a constant and integrated approach to critical analysis, evaluation and synthesis of new and complex ideas, information and issues. G1
- Identify, conceptualise and offer original and creative insights into new, complex and abstract ideas, information and issues. G2
- Develop creative and original responses to problems and issues G3
- Deal with very complex and/or new issues and make informed judgements in the absence of complete or inconsistent data/information. G4

Table 3: Evidence for Generic Cognitive Skills

Learning Outcomes	Evidence
Apply a constant and integrated approach to critical analysis, evaluation and synthesis of new and complex ideas, information and issues. **(G1)**	Report Page 9 Data Analysis
	Report Page 16,17 Discussion of Findings
Identify, conceptualise and offer original and creative insights into new, complex and abstract ideas, information and issues. **(G2)**	Report Page 16,17,18 Discussion of Findings
Develop creative and original responses to problems and issues **(G3)**	Report Page 9 Methodology
	Report Page 17,18 Discussion of Findings
	This paper 'Outcomes and Impact'
Deal with very complex and/or new issues and make informed judgements in the absence of complete or inconsistent data/information. **(G4)**	Report Page 17,18 Discussion of Findings

4. Communication, ICT and numeracy skills

The SCQF criteria under this heading require demonstration of the ability to use a significant range of advanced and specialised skills as appropriate to a subject or discipline – for example

- Communicate at an appropriate level to a range of audiences and adapt communication to the context and purpose. C 1
- Communicate at the standard of published academic work and/or critical dialogue and review with peers and experts in other specialisms. C2
- Use a range of software to support and enhance work at this level and specify software requirements to enhance work. C3
- Critically evaluate numerical and graphical data. C4

Table 4: Evidence for Communication, ICT and numeracy skills

Learning Outcomes	Evidence
Communicate at an appropriate level to a range of audiences and adapt communication to the context and purpose. **(C1)**	This paper Section 6 Outcomes and Impact
Communicate at the standard of published academic work and/or critical dialogue and review with peers and experts in other specialisms. **(C2)**	This paper Section 6 Outcomes and Impact
Use a range of software to support and enhance work at this level and specify software requirements to enhance work. **(C3)**	This paper Section 6 Outcomes and Impact
Critically evaluate numerical and graphical data. **(C4)**	Report Page 4, 5 Paragraphs 6, 1 highlighted

5. Autonomy, accountability and working with others

The SCQF criteria under this heading require demonstration of the ability to:

- Exercise a high level of autonomy and initiative in professional and equivalent activities. A 1
- Take full responsibility for own work and/significant responsibility for the work of others. A 2
- Demonstrate leadership and/or originality in tackling and solving problems and issues. A3
- Work in ways which are reflective, self-critical and based on research evidence. A4
- Deal with complex ethical and professional issues. A5
- Make informed judgements on new and emerging issues not addressed by current professional and/or ethical codes or practices. A6

Table 5: Evidence for Autonomy, accountability and working with others

Learning Outcomes	Evidence
Exercise a high level of autonomy and initiative in professional and equivalent activities. **(A1)**	This paper Section 7 Reflections on Research
Take full responsibility for own work and/significant responsibility for the work of others. **(A2)**	This paper Section 7 Reflections on Research
Demonstrate leadership and/or originality in tackling and solving problems and issues. **(A3)**	Report Page 9 Methodology
	Report Page 19 Conclusions and Recommendations
	This paper Section 7 Reflections on Research
Work in ways which are reflective, self-critical and based on research evidence. **(A4)**	Report Page 11 Strengths and Limitations
	This paper Section 7 Reflections on Research

Deal with complex ethical and professional issues. **(A5)**	Report Page 17 Discussion of Findings
	This paper Section 7 Reflections on Research
Make informed judgements on new and emerging issues not addressed by current professional and/or ethical codes or practices. **(A6)**	Report Page 9 Methodology
	Report Page 10 Ethical Issues
	Report Page 13 Findings: Young Adults
	Report Page 17,18, Discussion of Findings
	Report Page 18, 19 Conclusions /Recommendations
	This paper Section 6 'Outcomes and Impact'

6. Outcomes and Impact

There have been a number of outcomes from this research. The first stage was to disseminate the findings to a range of audiences. The report, therefore, was presented internally to the CHAS Senior Management Team, Board of Trustees, young adults who use CHAS hospice services and their families and to all CHAS staff. Externally the findings were presented to health and social care professionals drawn from across Scotland at the CHAS Seminar and AGM in November 2008. Subsequently, an abstract (attached as Appendix 1:3) was submitted, peer reviewed, and the paper accepted for presentation at the Help the Hospices Conference in Harrogate in November 2009. This conference was attended by 600 delegates drawn from across the UK and internationally. The conference slides from Help the Hospices are attached as Appendix 1:4. **(C1,2,3)**

Since the research report was presented, a staff group to review practice and service provision. Following a review of our care provision, further services have been developed for this group, including additional weekend breaks, community based activities and additional support from out home care team. **(P6, KU3, A6)**

Young adults within CHAS are also much more empowered as a Young Adult Council is now also in place with membership drawn from the young adults who use our services.

They too are contributing to the review of our practice and the development of services to them. **(KU3, P6, G3, A6))**

I have also been instrumental in setting up discussions between CHAS and a number of external organisations with a view to partnership working. The Young Adult Council themselves are also beginning to identify partner organisations. **(KU3, P6, G3, A6))**

Whilst there is still much work to be done to address the complex issues of life limited young adults, it is clear that the research has already contributed to improved services in CHAS for this group.

7. Reflections on Research (A4)

I embarked on this project shortly after completing my MSc and I found it both rewarding and exciting to be able to apply my research skills learned throughout my period of study. It was also challenging to be commissioned to undertake research within my own organisation as whilst I had undertaken many projects in the organisation with the aim of influencing and developing practice, these were all undertaken by me in my role as an MSc Student at Dundee University. This time I undertook the research as a senior manager in CHAS. One of the main challenges associated with this was establishing credibility as a researcher amongst senior colleagues as my previous research experience appeared not to be recognised. Mike Naulty from Dundee University was, therefore, contracted by CHAS to have a quality assurance role in the project. I was approached on a number of occasions by colleagues and requested that I 'take advice' from them before finalising the report and the outcomes. It was difficult to balance the role of staff member with researcher and to resist the pressure to 'come up with the right answer'. I had to make it clear on a number of occasions that I was working within the University of Dundee, School of Education, Social Work and Community Education Research Ethics Code of Practice and that as a researcher, I had a professional and ethical responsibility to report the findings honestly and objectively, whatever these turned out to be **(P1,A1, 3, 5).**

On reflection one of the challenges and potential weaknesses of this project, was working with three colleagues who had no previous research experience. My responsibility was, therefore, to lead the design and structure of the research, including methodology, and to ensure that all stages were carried out to the highest standard. The strength of the research therefore relied, on how well I conveyed to others the principles of qualitative research, the boundaries of their role as interviewers and the considerations of being a practitioner researcher. I approached this over three sessions where I applied these topics to the context of our research project. I found that sharing skills with others was an excellent way of embedding and sharpening my understanding **(A1 Autonomy and initiative; A2Responsibilty for own/others' work; A3 Demonstrate leadership)**.

I have learned the importance of a realistic and effective timetable for research projects. Time allocated to the young adult study was too short and the timescale was set for us with no possibility of negotiation. This meant that preparation time with my colleagues was shorter than I would have liked. If I were to undertake a similar study again, I would ensure the timetable included sufficient time to prepare and plan with colleagues.

At the same time, my colleagues also brought significant expertise in working with life-limited young adults which I did not have. I believe that this strengthened the project considerably. They were chosen to be involved because of their expertise in the field of life-limited young adults, particularly their communication skills with this group, some of whom had limited ability to communicate verbally. Whilst I designed the questions to be used in the semi-structured interviews they advised on how these should be adapted to enable the young people to really engage with the questions. One colleague also adapted these questions for use with 'Talking Mats' and Symbol Boards for young people with no verbal communication skills. This meant a more inclusive project and ensured that a broader range of hospice users were enabled to take part and voice their own opinions **(A1,2,3,4, 5)** .

There may be an element of bias in the study because of the closeness of the staff to the young people involved. This will have been mitigated in part by the process of group

analysis and checking back with a sample group of the young people themselves. **(A1,2,3,4)**

On reviewing the report again for this paper, I feel that the research report could be much improved. One of the challenges which I faced in leading the research was the time constraints imposed by the organisation and the workload of each of us who were involved with the study and I think this comes through in the report. Having recently completed my MSc before writing the report, I enjoyed not being constrained by a word limit. In retrospect I have learned that had I been more disciplined, I would have undertaken further analysis of data and sharpened the writing to produce a sharper, clearer and more succinct report **(A 4)**.

I did, however, very much enjoyed sharing my enthusiasm and knowledge of research. In doing so I further developed my knowledge and skills as I prepared the sessions for my colleagues on qualitative research. I have learned a great deal from my colleagues about the approach to communication with young adults and would like to learn more about using some of the methods which they brought to the study for people with no verbal communication skills. I have also very much enjoyed leading some of the resulting developments in CHAS to address the care of life-limited young adults.

References

1. Scottish Curriculum and Qualifications Framework (2003) Level 12 doctoral level criteria. Retrieved on 10 October 2009 from www.scqf.org.uk.

APEL CLAIM PART 1 Appendix 1:1

SO WHAT ABOUT US?

RESEARCH REPORT

A research study into the needs and aspirations of young adults with palliative care needs.

Ros Scott, Sharon Ballingall, Amanda Stark, Judith Neil

Acknowledgements

We would like to thank the young adults, their families and carers and CHAS staff who gave so freely of their time in taking part in this research. We would also like to thank Mike Naulty of Dundee University for his guidance and support.

Contents

Introduction

The Children's Hospice Association Scotland (CHAS) has undergone significant change and growth since its inception in 1992. Having successfully developed two children's hospices and a hospice at home service, CHAS prides itself on the strong values upon which it was founded and which continue to guide its work and development. The purpose of the organisation is to provide hospice care to children with a life-limiting condition, support to their families and to offer this care to all who need and want it. Very few of the children cared for have cancer, with most having very complex medical needs arising from progressive, life-limiting, degenerative conditions. Care provided includes respite, home, emergency and terminal care, and support extending to the whole family. It may start at the point of diagnosis, lasting through bereavement, for as long as the family require. Consequently some children will be cared for over a number of years and be well known to the staff within the hospices. Working to this purpose has engendered a strong culture of embracing all who need such care for as long as is required.

During the past twelve years since the opening of CHAS's first hospice in 1996, medical advances have influenced the progress of some children's conditions, with many young people living longer than expected **(KU1 Critical overview; KU2 Detailed knowledge).**

Whilst this is an extremely positive development, the result is that hospices, which were set up to care for children, are now also caring for a group of young adults living into their mid-twenties and beyond. With continued developments in medical care, the numbers of young people in this position is set to rise. These young adults are living with children's conditions and there are few services, at present, set up to cope with their needs **(KU1 Critical overview ; KU 2 Detailed knowledge)**.

This, therefore, poses a major challenge for all children's hospices, and most especially for CHAS, as the organisation currently reviews and develops its strategy for the future. One of the key considerations must therefore be how best to approach the support of this group of young hospice users **(KU 1 Critical overview; 2 Detailed Knowledge)**.

Context of the Research

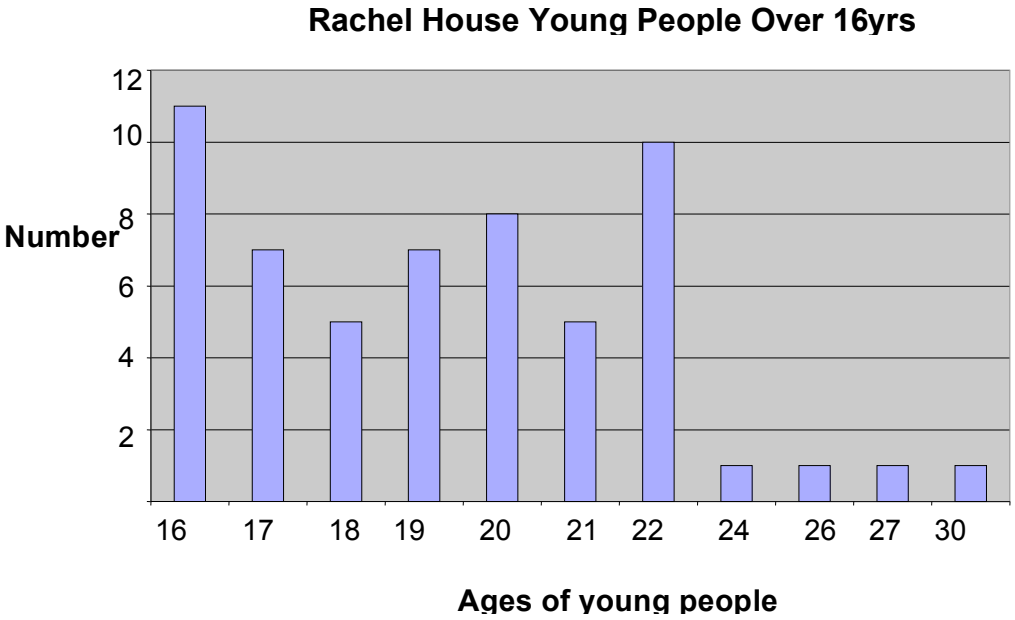
Children's hospices in the UK face a growing population of young people still accessing care in their late teens and mid twenties and hospices have approached this in a variety of ways. Of 11 hospices contacted in the course of this project, five services discharge young people from their care between the ages of 17 and 24. Two hospice services have purpose built units for young adults whilst four hospices are either in the planning or development stages of dedicated facilities for this group. One of the hospices which currently discharges young people at 17 years of age has recognised the need for a hospice for young adults, but lack of funding has prevented any developments in this area.

In common with other children's hospices, the issues facing CHAS in relation to the care of this group have emerged over time. Until the CHAS Key Strategy Document was developed in 2007, these had not been addressed strategically by the organisation. In CHAS, the number of teenagers and young adults being cared for is now a significant percentage of the user group. To understand the full extent of this it is important to consider the current CHAS statistics for young people aged 16 years and over **(KU1 Critical overview; C4 Critically evaluate numerical data)**. At the time of this study CHAS currently supports 182 families, 112 at Rachel House and 70 families within Robin House. Of the young people currently supported by CHAS 71 (39%) are 16 years and older. These figures in the main reflect the advances in medicine which has led to longer life expectancy for boys with Muscular Dystrophy. The figures in each hospice at the time of the study were as follows:

Rachel House

In Rachel House 57 young people are over 16 years of age, a total of 50% of the current users of which:

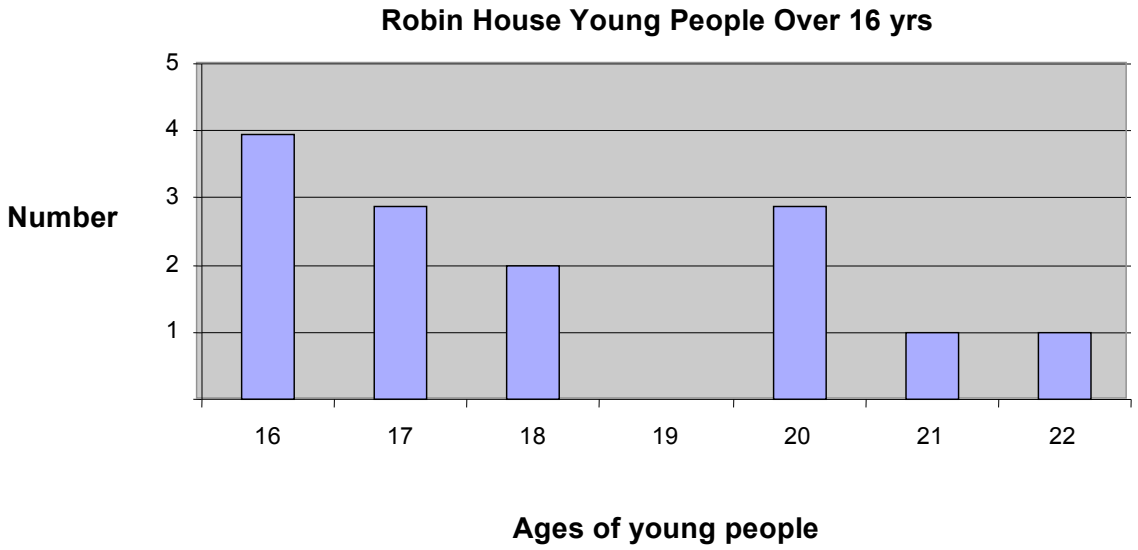
- 12 do not regularly access bed nights
- 7 do not access CHAS services
- 17 may find it challenging to share their views because of communication difficulties
- 38 can articulate views or opinions



Robin House

In Robin House 14 young people are over 16 years of age, a total of 20% of current users of which:

- 10 of this group have communication difficulties
- 6 of this group can articulate opinions



During the past three years Rachel House figures for supporting young adults have steadily increased and as such are likely to have future implications in planning services for young people of 16 and over.

Consideration must also be given to the fact that both Rachel and Robin House are registered with the Care Commission as services for children and that there may be implications in the future for the organisation in continuing to provide care to both children and young adults.

As life-limited young people live longer, their development continues in the same way as other young people leading to them to have similar expectations of independence. The challenge therefore is to identify the needs and aspirations of these young people and their families to ensure that suitable provisions are developed to address their unique needs **(KU1 Critical overview ; KU 2 Detailed knowledge)**. Growing anecdotal evidence from the young people, recognition of the increasing impact on service delivery coupled with ongoing discussion and debate on these issues within children's palliative care in the UK have prompted CHAS to undertake this piece of research.

Purpose of the Research

The purpose of this research is to:

- identify the needs of young adults in CHAS with a life limiting condition
- seek the views of young people, their families and care staff of the appropriateness of the current care offered to this group
- make recommendations for service development within CHAS
- influence and develop practice in the field of young adults and palliative care **(KU3 Generated through personal research)**.

Literature Review

It is clear from the review of the literature that there is a recognition of the unique needs of young adults with life limiting or life threatening conditions. Thornes (2001) states that "young people with palliative care needs should be recognised as a distinct group with physical, psychological and development needs that are significantly different from those in children and adults" **(KU 2 Detailed knowledge ;KU3 Generated through personal research)**.

Much discussion in the literature surrounds the importance of the effective transition of young people from paediatric to adult services. Viner (2008), states that this is a major consideration for the NHS and identifies three key areas which must be in place to ensure effective transition. These are identified as: a change in the attitudes of staff; a change to current systems to ensure "effective transition programmes are in place" and young people must be enabled and encouraged to be equal partners in the transition process **(KU1 Critical overview ; KU 2 Detailed knowledge)**.

Research also recognises the complexity of the issues involved in providing care for young adults with life limiting conditions as consideration must be given not only to the medical needs, but also to developmental and emotional needs. This is more complex given the findings of Stam et al (2006) which identified a slower developmental path than that of other young people of a similar age **(KU1 Critical overview ; KU 2 Detailed knowledge; KU 3 Generated through personal research)**.

Better Lives: Better Care produced by the Department of Health in England (2008) evinces a vision that children and young people will "have equitable access to high-quality, family centred, sustainable care and support, with services provided in a setting of choice, according to the child and family's wishes" **(KU1 Critical overview ; KU 2 Detailed knowledge)**.

CHAS has also recognised the need to consider and address the issues of young adults and this is highlighted in two main documents. Both the CHAS Key Strategy Document and the recent research undertaken by Stirling University Cancer Care Research Centre to identify future research priorities for CHAS highlight the requirement for the organisation to address the needs of this group.

The CHAS Key Strategy Document, May 2007 states as one objective: "Agree 16+ Care model and make recommendations on delivery by end 2008." It outlines the following actions:

- discussion and consultation with young people, families, staff and key stakeholders.
- plan and commission research
- report to CHAS Board

The report from Stirling University Cancer Care Research Centre on the future priorities for CHAS made the following recommendation:

"Consider conducting a needs assessment of young people (16+) with life-limiting conditions from the perspective of the young people themselves, their parents and professionals. The needs assessment should consider the following issues;

- Identify the care and support needs of young people from all perspectives;
- Review the psychological support CHAS currently provides to young people (16+) who know they have a life-limiting condition; and
- make recommendations for staff training, development and support" (University of Stirling, Cancer Care research Centre, September 2007)

It is clear from the literature review that there is a recognition of the urgency of addressing the needs of this particular group and there are many models which address the pathway from paediatric health care services to adult services. However, in considering the specialist palliative care needs of young adults, there are more questions raised than answers relating to transition **(KU1 Critical overview ; KU 2 Detailed knowledge; KU 3 Generated through personal research)**.

Anecdotal evidence from children's hospices would suggest that there is little provision available for young adults with life-limiting conditions. The question "transition to what?" remains largely unanswered **(KU1 Critical overview ; KU 2 Detailed knowledge; KU 3 Generated through personal research)**.

Kennedy et al (2007) assert that "Increasing evidence shows that adverse health consequences occur when inadequate transition arrangements are in place". age **(KU1 Critical overview ; KU 2 Detailed knowledge; KU 3 Generated through personal research)**.

This then should be of significant concern to all those who provide palliative care services to young adults and highlights the importance of this study **(KU1 Critical overview ; KU 2 Detailed knowledge; KU 3 Generated through personal research)**.

Methodology

This research employed qualitative methods of data collection. Quantitative data was also gathered to give context to the qualitative data. Because of the sensitivity and complexity of the subject matter it was difficult to use collaborative methods of data collection. Consequently collaboration was used during the design stages of the research. At an early part of the planning process, initial discussions took place with the Senior Management Team, Chief Executive and Board of Directors regarding the focus and plans for the project. This was an essential step in obtaining permission from the organisation and in maximising the effectiveness of the project outcomes. A number of staff were engaged in discussions of the key issues and in identifying the research questions. Staff were also involved in the design and piloting of data collection tools **(P1 Skills associated with discipline; P2 Range of complex skills; P3 Standard research instruments; P4 Design and execute research)**.

This is a very sensitive area for both young people and their families and methods employed in the research required to take account of this **(P1 Skills associated with discipline; P4 Design and execute research)**. Young people with life limiting illnesses are generally anxious about their future needs and deteriorating condition, therefore the subject had to be sensitively approached by people who understood their apprehension and feelings. Consideration was also given to the fact that the young people involved might choose to use this opportunity to discuss additional thoughts, concerns or issues. It was important therefore that interviewers were equipped to deal with such situations. It was decided to involve staff with experience in this area to conduct the interviews and focus groups **(P2 Range of complex skills)**.

The following methods of data collection were used:

- individual semi - structured interviews
- two focus group discussions

Most interviews were held face to face but because of the geographic spread of the young people some telephone interviews were required.

It was also important to consider in the design of data collection methods that a number of young people might have communication and or cognitive difficulties. It

was decided in such cases to use a mosaic approach to gather a picture of their views **P3 Standard research instruments; P4 Design and execute research)**. This involved the use of 'Talking Mats' developed by the AAC Research Unit and symbol boards. Where young people were unable to use either of these methods interviews will took place with significant people, such as parents or guardians, involved in caring for the young adults **(P5 Demonstrate originality; P6 Context of new problems; G3 Creative and original responses; A3 Demonstrate leadership; A5 Complex issues)**.

Data Analysis

Data analysis took place in several stages. The first phase involved the analysis of the interviews to gain an overall sense of the findings, identify emerging themes and issues and identify topics to be covered by the focus groups.

Findings from the interviews and focus groups were initially written up. Analysis of this data was undertaken by all involved in the research in a group setting. Data was sifted and coded into themes by the group. This was further revised, summarised and coded again. By analysing data in this way, bias was reduced and validity strengthened. A sample of participants were asked to check the initial write up of the findings to check for resonance and validity **(G1 Integrated approach; P1 Range of skills; P2 Complex skills; P3 Standard techniques; P4 Design and execute research)**.

Sampling

Sarantakos (2005) considers that qualitative researchers "employ sampling procedures that correspond to the philosophy of this type of research and that are less structured, less quantitative and less strict" than those used by quantitative researchers. In considering the nature of our research, it was important that our sample was representative of age, gender, medical condition and geographical spread. We therefore undertook a form of non-probability sampling to meet these criteria as far as possible. Our sample group of young people included:

- 23 young people aged between 16 and 24 who could articulate their views
- 3 young people aged between 16 and 24 who required additional communication assistance or advocacy support
- 19 parents or carers of young people
- 12 staff from Rachel and Robin House

Of the young people, carers and staff invited to take part, two young people declined. **(P1 Skills associated with discipline; P2 Range of complex skills; P3 Standard research instruments; P4 Design and execute research)**.

Ethical Issues (A5 Deal with complex ethical issues)

The University of Dundee, School of Education, Social Work and Community Education Research Ethics Code of Practice was adhered to throughout the study. This was made clear to all participants and copies of the code offered. The project was also mentored throughout by Mike Naulty, Associate Dean, School of Education, Social Work and Community Education, University of Dundee.

As mentioned previously, permission was sought from CHAS before undertaking the project.

Uppermost in our consideration of the ethical issues involved in this research, was the sensitivity of the topic. In exploring experiences and aspirations of young people our approach required to be considered and empathetic. In advance of the study, we ensured that the effective support was available to all who took part, should involvement in the research cause participants to become distressed. Participants were advised of these arrangements before consenting to take part **(P1 Skills associated with discipline; P2 Range of complex skills; P3 Standard research instruments)**.

The reasons for choosing the focus of the research, and how we intended to gather and analyse data was made clear to all participants. This was achieved through an information sheet and also by explanation in ways which could be understood by participants with communicative or cognitive impairment. All participants were invited to take part and asked to give consent. It was also made clear that potential participants had the option not to take part and should they decide to do this, that this would not in any way affect the care offered to them by CHAS. Prospective participants were also assured that they retained the right to withdraw from the project at any stage **(P1 Skills associated with discipline; P2 Range of complex skills; P3 Standard research instruments)**.

Participants were also assured of the confidentiality of their responses and that all necessary steps would be taken to ensure that the project report would contain no names or information through which individuals may be identified. To assist with this, interview outlines and focus group notes used only codes for administrative purposes. Participants were assured of the methods of storage, handling, and disposal of data both electronic and paper that all information was handled in accordance with the Data Protection Act (1998 **(P1 Skills associated with discipline; P2 Range of complex skills; P3 Standard research instruments)**.

Strengths and Limitations

Although sample sizes for young people are significant with 37% of young people supported by CHAS taking part in the study, not all young people's views have been taken into consideration. This could mean that there may be a bias to the study. However, a number of methods of data collection were used to strengthen

the reliability and validity of the data through triangulation. This also helped to overcome the limitations of methods. The partiality of the researchers could also be considered as a limitation, however group data analysis and member checking of the data and subsequent report were undertaken to minimise this and to ensure the accuracy of findings **(A4 Demonstrate leadership)**.

Findings

The interviews elicited a rich source of varied data. In analysing the findings from interviews with young adults, their parents or carers and staff, six clear themes emerged: the limitations of the service currently offered to young people by CHAS; the importance of staff; the role of CHAS in providing care; unmet needs; socialisation and aspirations for the future.

Findings from Young Adults

All young people who were interviewed stated that CHAS had a role to play in supporting their adult needs. The two key areas highlighted were the importance of the respite care and age appropriate activities. Findings demonstrated that young people valued respite as giving them a much needed break from their families. It was interesting to note however that young adults also viewed respite as being important in giving their families a break from them. Eighteen respondents saw CHAS's role as providing age appropriate activities whilst seven identified community support. Sixteen respondents identified that CHAS needed to provide more appropriate facilities for young adults in either a separate building; a special area within the hospice or drop in facilities. One young person stated that without CHAS there was nothing.

The importance of the relationship with staff was evident, particularly in terms of trust, flexibility, knowing staff well and the opportunity to talk to staff. One young man spoke of the importance of knowing staff: "It is much more stressful to get to know someone new when it's about caring for your personal care or when you're really not well". Young people also highlighted however that staff needed to have the right skills to work with young adults and for staff to want to work with this age group. Two respondents, however, indicated that they had experienced negative relationships with staff whilst another young person indicated that there were not enough staff and that this led to restrictions on activities during their stay.

It was clear from the findings that young adults experienced a range of significant limitations in their lives. Sixteen respondents cited a range of contributory factors including their dependency on others for care, including assistance with eating and personal care. Others spoke of a lack of accessible activities which other young people of their age were able to undertake such as going to pubs and clubs. A number of the young people interviewed spoke of their isolation as a result of having few, if any, social networks. As one respondent highlighted: "When I'm at

home I go to bed at 10pm so I am not able to go to clubs. My disability restricts me 'cause I am not able to put myself to bed and get out. There are less restrictions at the airport!"

The findings also indicated that the needs of young people had changed as they became older. Most of those interviewed identified that their deteriorating condition had led to increased care needs leading to dependency on others: "I've got sicker…..I didn't need too much help when I was younger, but I do now. Like I need someone to wash my hair 'cause I'm too tired. I'm losing my physical abilities, I know I'm losing them- it takes longer to get changed and do things." Another spoke of the impact of deterioration:" I'm getting a lot weaker. It does freak me out."

In reporting on the impact of the deterioration of their condition, one young person highlighted his frustration in referring to a requirement for ventilation and significant levels of care. He commented that the level of care he required "takes forever."

Six young people reported that they liked the hospice for the social aspect and viewed it as a safe and important alternative to hospital. Of this group four respondents reported that they were treated like adults and valued being able to stay up late which they could not always do at home: "Mum and Dad get too tired to stay up late at home". Young people valued the company and friendship which visiting the hospice afforded them.

Conversely, however, the majority of young people did not feel that the children's hospice environment as it was met their needs. The findings indicated that many young adults struggled with the mix of ages and with 'too many wee kids' which resulted in them being restricted in their activities and in the provision of activities. These were also not always felt by the young people to be age appropriate. One respondent stated: "one night I wanted to watch a film that was a 15 but I couldn't because it needed a pin number and I'm over 15 – I'm 20!" One respondent had lost trust in staff whilst another felt that CHAS had not developed to meeting the changing needs of young adults; "…DMD (Duchenne Muscular Dystrophy) life expectancy is better and CHAS haven't moved with the times". The need to allow girlfriends to stay in the hospice was also raised by one young person.

A number of respondents spoke of the importance to them of forming relationships, in particular sexual relationships and that they needed help to achieve this. It was clear from the findings that for a number of respondents, relationships, sex and having children were very important. "To be honest the only thing I can think of just now is experiencing a sexual relationship. It is very high on my priorities…it is something I want to experience" **(A5 Deal with complex ethical issues)**.

In addition to this respondents reported a diverse range of aspirations. Those cited most frequently included going on to college or university; living independently with their own carers; whilst others included the opportunity to have a job and a career, flatmates and to have more control over their lives.

Findings from Families

The findings from families largely supported those of the young people in most areas and clearly identified their dependence on CHAS for support: for themselves; the young adults; and from other parents. This group also identified the key role of staff in providing support, the high ratio of staff to families; the continuity and importance of the trusting relationship with them and that "nothing is a problem" to staff.

Fifteen respondents identified respite from CHAS as being very important to them in giving them time for themselves but also giving a break from the family for the young adult. A significant number of families stated that they would not be able to cope without CHAS. A number of respondents indicated that it was the only support which they had. "It's a life line for us. It's the only respite we get."

Families also discussed the impact of disease progression on the young people leading to increased care needs and dependency. They too recognised the limitations and isolation which resulted from this. These included a lack of social opportunities; age appropriate activities; stimulation and community support. They also reported that young people had unmet needs in terms of relationships, sex and girlfriends. One parent in commenting on this isolation stated: "His friends have moved on, they used to come regularly to take him out."

Respondents in this group identified a continuing role for CHAS in supporting young adults with regard to their care needs; providing stimulation and a good range of age appropriate activities; providing more community support and more access to the hospice services. "We need to think seriously about an adolescent service, as our children have lived longer than expected. There are no provisions."

Six respondents stated that they were unable to access this support any where else. A number of families had experience of adult hospices but felt that they were not the right place for their young person. One parent stated:" …we looked at other resources – there was no where for x to go apart from staying in hospital and that's no life for x. There were no other suitable resources that x could access."

Respondents from this group had fewer aspirations for the young people than the young people themselves. Only two respondents highlighted independence as important, with most focussing on quality and length of life. Three of the families hoped for care for as long as it was needed; sheltered accommodation or day care.

Findings from Staff

The findings from staff largely supported those of the young people and their families but echoed those of the young adults more closely. The majority of respondents in this group stated that the hospices as they were currently were not the appropriate place to care for young adults. The reasons for this were cited as

significant diversity of the ages of those cared for in the hospices. Staff reported that as a consequence of this young adults lost out in terms of their needs being met.

Not all staff agreed with this however with a small number indicating that the hospices were the right place for young adults to be cared for as they developed trust in the staff and derived friendship and support through using the hospices. Staff were of the view, in common with the young adults and families, that there were no alternative services available to this group. One member of staff stated: “a lot of these families have no where else to go, it is the only respite they access.”

Overwhelmingly the findings from staff indicated that CHAS has a role to play in supporting young adults but that this needed to be a separate facility. Findings from this group also indicated that CHAS has a key role in providing respite care to give both parents and young people a break from each other; to offer opportunities and an environment where end of life issues may be broached and to advocate for the needs of this group. One respondent stated: “adolescence is a difficult time; families need more support at this time from people who they know and trust, and who understand the turmoil of end of life care”. It was also considered by this group that CHAS had a role in providing age appropriate activities for this group which could be tailored to individual needs. A small number of respondents reported the need to develop more community support for young adults.

It was recognised by staff however that they needed to be appropriately skilled to care for this age group. One respondent indicated that as they had been recruited to work with children they had not expected to then be involved in caring for adults. Findings indicated that staff felt strongly that young adults are affected by different issues from children and consequently have very different care needs. One member of staff stated that the family centred care provided by CHAS was not what young adults required. A few respondents supported the view of young adults that it was important that staff caring for this age group were not simply rostered to work in this area but that they should have a specific desire to work with this group.

Findings from staff also identified that young adults lacked social opportunities and the chance to form relationships. Relating to this, respondents indicated that there were significant training needs for all staff in caring for young adults. Areas highlighted included: dealing with adolescents; sex and relationship issues; young adult behaviour; communication skills and self-administration of medication.

Findings From Focus Groups

Three focus groups were held: one with young adults and two with staff. Because of geography and potential impact on the service of staff travelling between Rachel House and Robin House, it was decided to hold one staff focus group in each

hospice. It proved difficult because of geography, timescales and family circumstances to bring together a focus group of parents.

The purpose of these sessions was to explore in more detail some of the themes arising from the individual semi-structured interviews.

The key topics covered by the focus groups included:

- the role of CHAS in the young people's future: sharing their vision – young people and staff
- the expectations of young people and staff of respite services and what these should provide
- the restrictions / limitations within a children's hospice
- suggestions for the improvement of the children's hospice services to young adults

The findings from the young adults group highlighted, once again, that they were keen to see CHAS provide more age appropriate care, support and activities being delivered in a young adult unit. They felt that the importance of such a unit would be for them to be with others of a similar age "at least 5 others". The findings indicated that young people needed the opportunity to experience a "parent free zone" but would like their siblings and friends to be able to stay also, even friends with a disability. Respondents also indicated that in such a service it would be important for them to have more independence and autonomy. Examples included choosing and shopping for their own food and cooking their own meals.

The issues of independence and autonomy also extended to the role of staff. Young adults reported that it was important that staff were there as a "safety net but not always man marking". Respondents also indicated that they did not want hospital style monitoring or notes for example, measurement of the amount of urine passed and size of bowel movements.

In considering the restrictions experienced in the children's hospice environment, findings supported those from the individual interviews with respondents indicating that staying out late; being able to watch age appropriate DVDs and activities were important. Some examples of such activities included being able to relax and have some alcohol with friends and the opportunity for intimate social interaction. The question was asked as to what was CHAS policy on relationships and one young person stated that "CHAS should allow adults to be adults".

The findings also indicated that care at home and community support was important to the young people with more opportunities for outings and meeting together. Transport was also cited as a problem and it was suggested that CHAS might have a role to play in assisting in this area.
The respondents indicated that the ideal solution was to have their "own place" but if that were not to be possible more community support was required.

Whilst recognising the restrictions for young people in the children's hospice setting, findings from the staff focus groups highlighted that staff were more divided about the role of CHAS. A small number of staff cited the need for a separate facility for young adults. Others highlighted the need to make "better use of the hospices we have- one as an adolescent unit and one as a children's unit."

Respite came through again as being important. In common with the young people, staff stated that the provision of home care and community activities were important. Staff felt strongly that the role of CHAS was to give young people the chance to be normal. Concern was however expressed about impact of the change of ethos from a children's hospice.

Findings indicated that respondents had a number of concerns relating to the provision of care to young adults and these included the skill mix of staff, the impact on staffing levels and staff training requirements. Staff in Robin House reported that the hospice requires a youth worker to lead work with young adults. The question was also asked as to whether it really was the role of CHAS to provide such services or if it was not more to provide direction and support for children and young people moving to adult services.

Undoubtedly, however the area of greatest concern surrounded the availability of funding and whether extra funds could be found to deliver a dedicated service to young adults: "Will something have to give if we go on to support young adults?" and "we need to work in partnership with others".

Discussion of Findings

It is evident from the findings that for CHAS there are many complexities which surround the care of young adults with life-limiting conditions and that there is no simple answer or 'quick fix'. However there is a consensus among young adults, families and staff, that services as currently provided by CHAS fall short of meeting the needs of the majority of young adults. There is also significant evidence to suggest that there are no other suitable services currently available to these life limited young adults which meet their needs **(G1 Integrated approach; G2 Creative insights)**.

Conversely, however, a small number of young adults and families report that the children's hospice services as currently provided do meet their current needs. This may well be linked, not only to the particular condition, but also to the developmental age of the young person and this area warrants further investigation. This would suggest that no one solution is likely to meet the needs of all young people over 16. Consideration may therefore have to be given to a range of approaches to care and support **(G2 Creative insights; G4 Complex and new issues)**.

It is clear that the findings from the interviews and focus groups with young people and the interviews with staff and families indicate that all three groups are agreed that CHAS has an important role to play in supporting the care and needs of young adults.

There is a dichotomy, however, between these findings and those from the staff focus group where respondents are divided as to whether CHAS should continue to support this group. This may be related to the significant concerns raised about availability of funding and the potential risk to the children's hospice service of developing an additional dedicated service for young adults **(G1 Integrated approach; G4 Complex and new issues)**.

In considering what the role of CHAS may be, the findings suggest the provision of: specialist care; support for young adults and their families; age appropriate activities and also to enable and empower young people to have more freedom. This issue may well challenge accepted boundaries of the role of specialist palliative care, particularly in relation to adults and serves to highlight the unique needs of life limited young adults as they struggle with the natural desires of adolescence and young adulthood and the impact of their life limiting conditions. CHAS may therefore have to consider what constitutes hospice care in relation to this group and how needs which may fall out with this area may best be addressed**.(G2 Creative insights;G3 Creative responses; G4 Complex and new issues; A5 Complex ethical issues; A6 Informed judgements)**.

This evident struggle was one of the most poignant aspects of the study. Just as young people are reaching a stage when their aspirations are independence, freedom to go out to socialise with their peers, stay up late, go to clubs and for a significant number, experience relationships - including sexual relationships their condition is deteriorating and they are more dependent on others, usually parents, for their care. As their peers are separating themselves from parental influence and establishing independence, many life limited young people are becoming increasingly dependent. Findings from the study highlight the resulting frustration and tension for both the young people and their families.

This may be reflected in the consensus from all groups of the importance of respite care, not only for the young people, but also to provide support for their families. Whilst the needs of young adults have been the focus of the study, the findings indicate that the families of the young people are very heavily dependent on the services provided by CHAS for support to enable them to continue in their caring role. This will be an important consideration for CHAS as the organisation seeks to address any approach to the care of young adults. Most services for adults may not necessarily take into account the needs of parents or carers when considering the design and provision of services **(G2 Creative insights; G3 Creative responses; G4 Complex and new issues)**.

An emerging theme from young adults, parents and a number of staff indicate the desire to see the development of young adult specific services. Consideration

must be given however to the impact which such a development could have on the occupancy levels of the hospices if 39% of current users are removed. This may also impact on the both the cost and cost effectiveness of continuing both services for children and the development of any new adult services **(G2 Creative insights; G4 Complex and new issues)**.

Yet not all young people may benefit from such a development as there are those who find current services appropriate to their needs. It can reasonably be concluded therefore that one approach to the care of young adults may not meet the needs of all concerned and it follows that a range of services may be required. Consideration is required as to whether such services could effectively be delivered by one organisation **(G2 Creative insights; G4 Complex and new issues)**.

One possible solution, which may warrant further investigation, might be the development of partnerships with appropriate organisations to broaden the range of expertise available. This would very much be in line with emerging developments in palliative care **(G3 Creative responses)**.

It is also interesting to compare the responses from the young adults about their aspirations for the future with those of their families or carers. It is clear from the evidence that families and carers have lower aspirations than the young people themselves and this might imply that the young adult's aspirations may not be shared by their parents. This will therefore require significant and sensitive consideration and may be an area of potential tension in any move to address the desire of young people to become more independent **(G2 Creative insights; G4 Complex and new issues)**.

There are clearly issues for the organisation in terms of staff skills and training requirements as evidenced by both young people and their families. A number of staff clearly feel the need for skills development to enable them to interact confidently and effectively particularly with issues relating to sex and sexual health. Findings from young adults also evidence the need for staff not only to have the appropriate skills but to have a desire to work in this field. This requires consideration by CHAS not only in addressing the issues raised in this research in the longer term, but in putting systems and services in place to mitigate these concerns in the immediate future **(KU3 Knowledge generated through personal research; G2 Creative insights; G3 Creative responses; G4 Complex and new issues)**.

Conclusions and Recommendations

The literature provides a range of research into the area of transition for adolescents and in some cases describes 'pathways' which facilitate the progression of young people with complex needs from paediatric to adult health

and social care services. The findings from this research would suggest however that there would seem currently to be a significant lack of services for life limited young adults and subsequently no services for these young people to move on to. This therefore leaves the organisation with some dilemmas. To care or not to care is the essence of the decision which CHAS must now make and if not CHAS then who? **(A6 Informed judgements)**.

It is clear however that the majority of young people and staff believe that CHAS has a role to play in their adult care. Families have also indicated that they are also dependent on the organisation for support. The philosophy of the organisation has always been that children, young people and families are at the heart of care and that services have been built and developed in response to their needs. This research would suggest therefore that CHAS not only has a key role to play in the care and support of this group, but also has a responsibility to respond to the needs expressed. This could present a valuable opportunity to engage with other organisations in exploring more widely the best approach to addressing the needs services life limited young adults and their families. It also presents an excellent opportunity to reach out to other life-limited young people who may potentially benefit from such services **(KU3 Knowledge generated through personal research; A3 Demonstrate leadership; A6 Informed judgements)**.

"So what about us?": what will happen to our life-limited young people who continue to live longer than expected? The authors would suggest that CHAS must continue to care for this group and lead the way in shaping and developing age appropriate services **(A3 Demonstrate leadership; A6 Informed judgements)**.

Time, however, is of the essence for these young adults and any response to address the needs evidenced in this research requires to be thorough, effective and most importantly, timeous.

Recommendations

The recommendations arising from the research are that:

- CHAS considers the most effective approach to address the findings of this research by setting up a short life working group comprising representatives from a range of CHAS departments, voluntary organisations and statutory services to consider the possible choices in developing palliative care services for this group of young people
- CHAS explores the possibility of partnership with appropriate organisations in taking forward services for young adults
- an assessment of facilities in CHAS is undertaken to assess how current services might be used and targeted more effectively in the short term
- a training needs analysis of staff is carried out to identify training needs and a learning and development programme introduced in response (**A3 Demonstrate leadership; A6 Informed judgements)**.

Further research is also required to identify how many young people not currently known to CHAS may need palliative care services and also to assess the psychosocial needs of parents and carers of this group and how families may be effectively supported in the future.

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Appendix 1.2

SCQF Level 12 - (SHE level 6, PG 2, Ph.D. – Doctorate is an examples of qualifications on this level)

NB: The descriptors set out the characteristic generic outcomes of each level. They are intended to provide a general, shared understanding of each level and to allow broad comparisons to be made between qualifications and learning at different levels. They are not intended to give precise nor comprehensive statements and there is no expectation that every qualification or programme should have all of the characteristics. The descriptors have been developed through a series of consultations and are offered as a first working guide and will be revised in the light of feedback on their use.

Knowledge and Understanding	Practice: Applied knowledge and understanding	Generic Cognitive Skills	Communication, ICT and numeracy skills	Autonomy, accountability and working with others
Characteristic outcomes of learning at each level include the ability to:				
Demonstrate and/or work with: ◦ a critical overview of a subject/discipline, including critical understanding of the principal theories, principles and concepts ◦ a critical, detailed and often leading knowledge and understanding at the forefront of one or more specialisms ◦ knowledge and understanding that is generated through personal research or equivalent work which makes a significant contribution to the development of the subject/discipline	Use a significant range of the principal skills, techniques, practices and materials associated with a subject/discipline Use and enhance a range of complex skills, techniques, practices and materials at the forefront of one or more specialisms Apply a range of standard and specialised research/equivalent instruments and techniques of enquiry Design and execute research, investigative or development projects to deal with new problems and issues Demonstrate originality and creativity in the development and application of new knowledge, understanding and practices Practice in the context of new problems and circumstances	Apply a constant and integrated approach to critical analysis, evaluation and synthesis of new and complex ideas, information and issues Identify, conceptualise and offer original and creative insights into new, complex and abstract ideas, information and issues Develop creative and original responses to problems and issues Deal with very complex and/or new issues and make informed judgements in the absence of complete or consistent data/information	Use a significant range of advanced and specialised skills as appropriate to a subject/discipline – for example: ◦ communicate at an appropriate level to a range of audiences and adapt communication to the context and purpose ◦ communicate at the standard of published academic work and/or critical dialogue and review with peers and experts in other specialisms ◦ use a range of software to support and enhance work at this level and specify software requirements to enhance work ◦ critically evaluate numerical and graphical data	Exercise a high level of autonomy and initiative in professional and equivalent activities Take full responsibility for own work and/or significant responsibility for the work of others Demonstrate leadership and/or originality in tackling and solving problems and issues Work in ways which are reflective self-critical and based on research/evidence Deal with complex ethical and professional issues Make informed judgements on new and emerging issues not addressed by current professional and/or ethical codes or practices

Appendix 1:3

Help the Hospices Conference

24-26 November 2009 Harrogate International Conference Centre

Abstract Submission

Ros Scott, Sharon Ballingall, Judith Neil and Amanda Stark,
Children's Hospice Association Scotland.

TITLE: "SO WHAT ABOUT US?"

Introduction

In recent years, medical advances have influenced the outcome of some children's conditions. Many young people are therefore living longer, becoming adults with children's life-limiting conditions and in the Children's Hospice Association Scotland, are now a growing percentage of the user group.

CHAS decided to undertake research to assess how effective our current services were in meeting the developing needs of this group.

Aims

The aims were to:

- evidence the needs of young adults in CHAS
- seek their views; those of their families and staff of the appropriateness of the care offered
- make recommendations for service development
- influence and develop practice in palliative care

Methods

Qualitative data was collected through individual semi-structured interviews and focus groups purposively sampled from both hospices. It was important to include young people with communication and or cognitive difficulties. 'Talking Mats', symbol boards and advocacy were also used.

Findings

The findings from this research would suggest however that there would seem currently to be a significant lack of services for life limited young adults and subsequently no services for these young people to move on to. The struggle for these young adults to be young people first and life-limited second was one of the most poignant findings from the study. These highlighted the frustration and tension for young people and their families as a result of increasing dependence with age. Whilst young people and their families indicated a

desire to continue to receive care from CHAS, they highlighted a need for a review of services provided to this group.

Conclusion

As a result of the research CHAS has embarked on a range of activities including, development of a young adult council; a review of services and exploration of partnership working.

APEL Claim Part 1 Appendix 1:4
Presentation to Help the Hospices Conference
November 2009

So What About Us?

Ros Scott
Director of Organisational Development

CHAS

- Founded in 1992
- Scotland's only children's hospice services
- 3 Hospice Services
  - Rachel House in Kinross
  - CHAS at Home
  - Robin House in Balloch
- 220 Staff
- 900 Volunteers

Context of Research

- Medical advances children's conditions
- Children's hospices in UK
- Wider discussions re transition
- Adults with children's conditions

CHAS Context

- Discussions with Board
- Anecdotal evidence
- 71 young people over 16
- 39% of hospice service users
- not all regularly accessing bed nights

Methodology

- Practitioner research
- Research team
- Purposive sampling: age and condition
- Data gathering:
  - semi-structured interviews
  - talking mats/symbol boards
  - focus groups
- Data analysis
- Ethical issues

Emerging Themes

- Limitations of service
- Importance of staff
- Role of CHAS
- Unmet needs
- Isolation
- Aspirations for future

Findings:Impact of Condition

- Dependency on others
- Increasing care needs
  - *" I've got sicker. I didn't need too much help when I was younger but I do now. Like I need someone to wash my hair 'cause I'm too tired.*
- Lack of accessible activities
- Isolation
- Anxiety
  - *" I'm getting a lot weaker. It does freak me out"*

www.chas.org.uk

Findings:Current Service

- Staff: relationship and trust
- Not meeting needs of majority
- Safe alternative to hospital
- Social aspects
- Diversity of ages
  - restrictions
  - lack of age appropriate activities
- *" CHAS hasn't moved with the times"*

www.chas.org.uk

Aspirations of Young People

- Relationships and sex
- College and university
- Live independently
- Job, career and flatmates
- To have more control

www.chas.org.uk

Role of CHAS

- Symptom control
- Respite care
- Age appropriate activities
- Community support
- Dependence on service
  - *" We need to think seriously about an adolescent service as out children have lived longer than expected. There are no provisions."*

www.chas.org.uk

Findings from Families

- No other provision
  - *" It's a lifeline for us. It's the only respite we get".*
- Adult hospices
- Importance of staff
- Value of respite
- Implications of illness for young people
- Aspirations not shared

www.chas.org.uk

Findings from Staff

- Hospices not appropriate
  - Diversity of ages
  - Young adults disadvantaged
- No other services
- Role of CHAS
  - Respite/end of life care/advocacy
  - Age appropriate activities/community support
- Lack of experience and skills

www.chas.org.uk

Focus Groups

- Need for specific services
  - Age appropriate care
  - Others of a similar age
  - More autonomy- shopping and cooking
  - Staff as safety net
- Young adults' wish list
  - Relax with alcohol and friends
  - Intimate social interaction
  - More care at home/community support
  - Allow adults to be adults

www.chas.org.uk

Focus Group:Staff

- Divided on issues of young adults
- Better use of hospice services
- Importance of providing respite
- Impact of change in service provision
  - Staffing levels and skill mix
- What is role of CHAS
  - Direction and support
- Funding concerns
- Importance of partnership

www.chas.org.uk

Conclusions

- Young people are young people first
- Current services falling short
- Lack of other provision
- "One size won't fit all"
- Clear role for CHAS
  - Specialist care/support for young people and families/age appropriate activities
  - Enable and empower

www.chas.org.uk

Challenges

- Challenging accepted boundaries
- Young person's struggle
- Different aspirations
- Needs of carers
- Appropriate staff skills and mix
- Strategic implications

www.chas.org.uk

Recommendations

- Commission short life working group
- Exploring possible partnership
- Assess how current service provision used and how these may be targeted more efficiently
- Learning needs analysis and training programme

www.chas.org.uk

What happened next

- Young Adult Council formed
  - Reviewing service provision
  - Recommendations to board
- Internal working group
  - Mapping current service
  - Assessing current service provision
- Identified external organisations
  - Exploration of partnerships

www.chas.org.uk

APEL CLAIM **Part 1**

Rosalind Scott
Matriculation No: 030015787

Research project: "So what about us?"

My role in this project was to structure the project, identify data collection and analysis methods, and teaching colleagues the principles of qualitative research. I discussed and agreed sample sizes and sampling methods with my colleagues. My colleagues undertook all the semi-structures interviews and focus groups with participants. My role in this was solely to support and to check on progress. Once all the data had been collected, I led my colleagues through the analysis of the data. I then wrote the research report which my colleagues then checked for accuracy.

The percentage of work undertaken by me in this project was 50%.

Signed: _____ **Signed:** PLEASE SEE OVER
Sharon Ballingall **Amanda Stark**

Signed: Judith Neil.
Judith Neil

APEL CLAIM **Part 1**

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Signed: _____ **Signed:** _____

Sharon Ballingall **Amanda Stark**

Signed: _____

Judith Neil

APEL CLAIM Part 2 **Rosalind Scott**

Matriculation No: 030015787

Contents

APEL CLAIM Part 2 **Rosalind Scott**

Matriculation No: 030015787

Volunteer Value Toolkit

Introduction

The purpose of this APEL claim is to demonstrate that the writing, research and publication evidenced in this paper was undertaken at doctoral level. This paper evidences the work undertaken in developing and writing "Volunteer Value. A toolkit for measuring the economic value of volunteers" published by Help the Hospices in 2007.

Structure of Claim Document

This paper provides evidence under the five headings of the Scottish Curriculum and Qualifications Framework Level 12 doctoral level criteria (SCQF, 2003) (Appendix1:2)

- Knowledge and Understanding
- Practice: Applied knowledge and understanding
- Generic Cognitive Skills
- Communication, ICT and numeracy skills
- Autonomy, accountability and working with others

Under each of the headings I will evidence the work undertaken for the project against the characteristic generic learning outcomes. As these are intended to give a general overview of learning outcomes, I will endeavour to match these as closely as possible, recognising however that not all evidence will match exactly.

Volunteer Investment Value Audit

Whilst the role of volunteers in terms of the contribution of skills commitment and time has been understood in some quarters, it has been difficult to quantify what this means to organisations in economic terms. Where the significance of donated time is not well understood, being able to illustrate this in economic terms can be of great value in helping to demonstrate the vital

involvement of volunteers in organisations. Volunteer Investment and Value Audit (VIVA) (1996), was developed by Katherine Gaskin of the Institute for Volunteering Research and is widely recognised in UK and Europe. This is a method of calculating the value of time donated by volunteers, estimating the costs involved in running the service and calculating the cost effectiveness of the voluntary service. Gaskin (1999) described the methodology involved in undertaking such an audit and published a self-help guide in 2003. **(KU 1 critical overview of subject/discipline)**

Background to Project

Gaskin was commissioned to undertake an in depth study of three hospices in England using the VIVA methodology for Help the Hospices (2003) to attempt to ascertain the value of volunteering in hospices in the UK.

Following this in 2006, a UK wide pilot study was undertaken by Help the Hospices in an attempt to encourage all hospices to use VIVA methodology to calculate and report on the economic value of the time donated by their volunteers. Having been involved in using VIVA within my organisation for a number of years, I was invited to be part of the steering group for the study in addition to my hospice organisation participating in the pilot.

There were two main aims of the pilot: one was to encourage the auditing of volunteer time alongside accounting procedures; the second was to benchmark the level of involvement and value of volunteers across hospices. This pilot involved 59 hospice services throughout the UK.

It became clear during this pilot that a number of hospices found it difficult to participate fully and some not at all as they had no effective mechanisms in place to collect the data required. I offered to develop a toolkit for use by hospices to audit and calculate the value of volunteering and was commissioned by Help the Hospices to take this work forward. **(KU1 critical overview of subject/discipline; KU2 critical knowledge at forefront of specialism)**

The resulting published document "Volunteer Value: A toolkit for measuring the economic value of hospice volunteers" is attached as Appendix 2:1

First Stage of the Project: Critical Analysis: Literature

Before starting the toolkit project, it was important to recognise that Gaskin had not only developed the VIVA model, but had also developed a self help guide. Whilst a need had been identified to develop hospice specific methods, permission was sought from Katherine Gaskin and the Institute of Volunteering Research to develop and publish a hospice toolkit from their recognised and published work. This permission was given willingly with the proviso that their work was appropriately credited. **(A 5 complex ethical issues)**

In order to develop the toolkit, it was necessary to critically evaluate the Volunteer Investment Value Audit (VIVA) (1999). In doing this I needed to consider the methodology and its applicability to the volunteering models in hospices.

The criteria for analysis included:

- the relevance of VIVA to current practice in hospices
- applicability of the VIVA methods when applied to hospice volunteering
- the extent to which effective benchmarking of results could take place

Whilst the broad methodology was indeed applicable to hospices, there was a stage of the process missing which assisted organisations with methods to collect their volunteer hours. This is a key step as without this it is not possible to apply the VIVA methods. **(P1 range of skills, practices associated with subject/discipline)**.

Reports of Previous Hospice Studies

Before developing the Toolkit, I also reviewed the reports of two hospice studies as previously outlined. From Gaskin's (2003) study of the economics of hospice volunteering, it was clear that the sample size of three hospices used in the first pilot was too small to draw any useful conclusions. The hospices were of very different sizes and structure as were the voluntary services. The figures which had subsequently been extrapolated from this study could therefore not be considered to be statistically significant. **(KU1 critical overview of subject/discipline; KU2 critical knowledge at forefront of specialism)**

The second study included 59 hospices which provided more reliable information. This calculated the value of the volunteer contribution in UK hospices to be in the region of £112 m. It asserted that if these services were to be provided by paid staff, hospice costs would increase by 25%. However, it was evident from this study that some hospices struggled to collect accurate statistics on the hours donated by volunteers. Therefore, if future VIVA studies were to take place and to provide useful statistical and benchmarking information for UK hospices, support and guidance was needed in order to ensure that effective data collection and analysis systems were in place. **(KU3 knowledge generated through research/contribution to development of discipline)**.

This, therefore, was the catalyst for the development of the Toolkit.

Second stage: developing the Toolkit

Critical analysis of the literature, however, was not enough to be able to develop the Toolkit. In order to consider the development of VIVA methods specifically for hospices, I required a detailed, in depth knowledge and understanding of hospice volunteering models; the range and type of volunteering roles in hospices; the difference in role types between children's and adult hospices. I had gained much of this through practice in both adult and children's palliative care and significant experience of application of VIVA within my own organisation over a number of years. **(P1 range of skills associated with subject; P2 range of practices at forefront of specialism)**

Because of the diversity within the cohort of UK hospices and the limitations of my own preferred methodology as being that of only one children's hospice practitioner, it was important to engage collaboratively with experienced colleagues in adult hospices of a different structure and size and to identify hospices for inclusion as case studies. **(P3 range of techniques of enquiry)**

Identifying hospices for case studies

The criteria for identifying hospices for case studies included:

- their knowledge of VIVA methods
- experience of VIVA implementation within the hospice
- existence/effectiveness of methods of data gathering

- size and structure of hospice
- type of hospice: adult/children's

(P3 range of techniques of enquiry)

Three adult hospices in addition to my own organisation were identified as being different sizes, with different voluntary services structures and having a range of different approaches with one hospice having just begun the VIVA process.

Initially I planned to present four detailed case studies of the implementation of VIVA within hospices. The purpose of this was to give the readership a range of approaches which could be adapted to their own setting, structure, resources and requirements.

As voluntary services are not always well resourced within hospices, it was important to include a range of systems from the simple to the more complex to allow the Toolkit to be used in a range of settings. If very technical and complex systems were the only option it would mean that hospices with few resources would be unlikely to engage with the Toolkit. **(P4 design and execute development projects to deal with new problems)**.

The structure of the Toolkit was designed to explain VIVA within the hospice context; the benefits of VIVA to organisations; methods for collecting hours donated by volunteers; calculating the value and cost effectiveness. To achieve this I needed not only a detailed knowledge of VIVA, but also an in depth understanding of the different volunteering roles; hospice models of care including adult and children's and in -patient, day care and home care. This knowledge and understanding was central to considering the development of methods of initial data collection for VIVA which could be widely applied throughout the hospice movement. **(P2 practices at the forefront of specialisms)**.

In developing the Toolkit, I also took into account how to convey the significant benefits of undertaking VIVA within hospices to the intended target audiences of the document. These audiences included Voluntary Services Managers; Chief Executives; Finance Directors and administrative staff and volunteers. **(C2 communicate to a range of audiences).**

I approached the three colleagues previously identified to discuss the project and to invite the involvement the four as case studies. All agreed to submit accounts of their approach to the implementation of VIVA. Two were very similar and one reported only partial implementation. As the Toolkit was not envisaged as a large document, I decided to select only two adult case studies with varying approaches and to write up my own organisation's approach. As far as could be determined, at the time of developing the toolkit, few other children's hospices had implemented this audit process.

Once the material was received from my colleagues, I reviewed and analysed these in the context of the rest of the text. I did not however edit these to ensure a consistent style and flow as I wanted to conserve the individual practitioner 'voice' from each of the hospice accounts. I felt that this would be of more value to readers. **(G1 apply integrated approach; G2 creative insights into new information)**.

Having discussed the challenges of collecting volunteer hours with a range of hospice colleagues, coupled with my detailed understanding of hospice volunteering models, I moved on to design simple forms based on those used in my own organisation which could be adapted to a wide range of settings. Consideration had been given to making these available electronically, however it was clear from initial research that some hospice Voluntary Services Managers had no access to computers and that a significant variation in software would make this challenging. **(P5 originality and creativity; C2 adapt communication to context and purpose)**.

Initial discussions with colleagues had also highlighted that not all hospices were willing to give Voluntary Services staff access to staff hourly pay rate figures to enable the most accurate use of VIVA. Some hospices felt that this was confidential information which could not be divulged. In order for all hospices to be able to use the Toolkit, including those without access to staff pay rates, it was important to provide some suggested hourly rates which could therefore be used for calculations. **(A5 deal with complex professional issues; G3 develop original responses)**

These figures were developed from research into the report from Help the Hospices (2006). Research was also undertaken through the internet to explore NHS salaries and honoraria, particularly for Chairs and Directors of NHS Trusts as these were believed to be closest to hospice pay rates. **(G4 complex and new issues; A5 as above; A6 informed judgements on emerging issues)**

Experience of Process

As the author and editor of the work, I was responsible for the administrative process, liaising with hospice colleagues and with Help the Hospices throughout the process. **(A1 high level of autonomy and initiative; A2 take full responsibility for own work)**. The initial draft was sent to hospice colleagues, Help the Hospices and to the Institute of Volunteering Research for appraisal and comment before publication. **(C2 critical dialogue)**.

The process of developing the Toolkit was most valuable in contributing to the development of my own knowledge and experience of the use of the Volunteer Investment Value Audit, particularly in the application of my experience to a range of other settings. It challenged me to review critically my own application of VIVA and to become creative in the development of new systems to allow other hospices to implement the toolkit easily within the resources which they had. **(A4 work in ways which are self critical)**. It also challenged me to think as a trainer as the Toolkit needed to enable those who had no prior experience or knowledge to undertake the audit with ease. **(A3 originality in tacking issues)**.

As a result of my work with the Toolkit, I have developed electronic methods of VIVA calculations through the use of Excel spreadsheets set up to undertake calculations for both calendar and financial years. The information was previously stored and reported in Word tables. **(C3 use range of software)**.

Once the Toolkit was published in 2007, I ran workshops on the value and implementation of the Toolkit at the InVOLVE Conference, the professional conference for Voluntary Services Managers in the UK and Ireland. On publication, the Toolkit was distributed to all hospices in the UK. **(C1 communicate to a range of audiences; C2 communicate at standard of published academic work)**.

References

1. Scottish Curriculum and Qualifications Framework (2003) Level 12 doctoral level criteria. Retrieved on 10 October 2009 from www.scqf.org.uk
2. Gaskin, K. (1999). Valuing volunteers in Europe: *A comparative study of the Volunteer Investment and Value Audit.* London: Institute for Volunteering Research.
3. Gaskin, K. (2003). *VIVA – The Volunteer Investment and Value Audit: A self help guide.* London: Institute for Volunteering Research.
4. Gaskin K. (2003).*The economics of hospice volunteering.* London: Help the Hospices.
5. Help the Hospices (2006). Volunteer value: *A pilot survey in UK hospices.* London: Help The Hospices.

APEL Part 2 **Appendix 2.1**

Copy of Booklet: Volunteer Value. A toolkit for measuring the economic value of hospice volunteers.

Available as published copy of booklet provided separately.

Reference:

Scott, R. (2007). *Volunteer value: a toolkit for measuring the economic value of hospice volunteers*. London: Help the Hospices. Available from http://www.helpthehospices.org.uk/our-services/publications/publications-catalogue/?24331707_entryid210=133259

APEL CLAIM Part 3 **Rosalind Scott**

Matriculation No: 030015787

Research Report: "Other People's Time"

Contents

APEL CLAIM: Part 3 **Rosalind Scott**

Matriculation No: 030015787

Research Report "Other People's Time"

Introduction

The purpose of this APEL claim is to demonstrate that the research and publication evidenced in the research report "Other People's Time was undertaken at doctoral level. This paper reports the work undertaken in piloting the Volunteering Impact Assessment Toolkit (2004) developed for the voluntary sector in the UK. The Children's Hospice Association Scotland (CHAS) was invited by the Institute of Volunteering Research to pilot this complex evaluation tool as they were keen to assess the efficacy of the materials in different sectors. This gave me the opportunity to research the impact of volunteering on CHAS's first children's hospice, Rachel House.

Structure of Claim Document

This paper is structured under the five headings of the Scottish Curriculum and Qualifications Framework Level 12 doctoral level criteria (SCQF, 2003) (Appendix 1:2):

- Knowledge and Understanding
- Practice: Applied knowledge and understanding
- Generic Cognitive Skills
- Communication, ICT and numeracy skills
- Autonomy, accountability and working with others

Under each of the headings I will evidence the work undertaken for the project against the characteristic generic learning outcomes. As these are intended to give a general overview of learning outcomes, I will endeavour to match these as closely as possible, recognising however that not all evidence will match exactly.

In submitting evidence against the learning outcomes, I have used 5 different tables, one for each of the 5 headings outlined above. The preparatory paper "Other Peoples' Time?" written in 2005 is attached as Appendix 3:1 along with a copy of the published paper from Voluntary Action which was published in 2006 as ''Volunteers in a Children's Hospice" as Appendix 3:2). The content of both documents is the same. The sections which are cited as evidence are highlighted in yellow in Appendix 3:1). I have used abbreviations for each learning outcome as outlined in the tables to reference evidence in the report in Appendix 3:1. Conference slides from the Children's Hospice UK Conference in May 2006 are attached as Appendix 3:3.

In all sections I have set out to evidence the learning outcomes in relation to my critical understanding of the theories, thinking and knowledge at the forefront of the issues around volunteering in children's palliative care, a much under researched area. I also evidence the use and development of skills, knowledge and understanding which resulted from my research and which I believe has implications for all organisations which involve volunteers in a challenging emotional environment.

3 Knowledge and Understanding

The SCQF criteria under this heading require demonstration of/ and or work with:

- A critical overview of a subject / discipline, including critical understanding of the principal theories, principles and concepts. KU 1
- A critical, detailed and often leading knowledge and understanding of the forefront of one or more specialisms. KU 2
- Knowledge and understanding that is generated through personal research or equivalent work which makes a significant contribution to the development of a subject or discipline. KU 3

The toolkit comprised a range of resources allowing for me to identify the best methods for my organisation. In considering the best resources for CHAS, I had to evaluate critically the materials provided and assess their suitability and applicability to a children's hospice environment. This meant reviewing all aspects of the toolkit through the lens of a children's

hospice and identifying materials which could be adapted, identifying questions and materials which would be insensitive and would need to be changed **(KU1 Critical overview)**. It was also important to consider the role and setting of the hospice in the wider community in order to assess which parts of the toolkit could be applied in this setting. As the only hospice organisation involved in then pilot, I had the responsibility to consider the wider context of hospice volunteering in order to evaluate critically the toolkit for use within the hospice movement **(KU 1 Critical overview; KU2 Detailed knowledge)**.

In critically analysing the toolkit, it was essential to understand the background to the development of the toolkit which was at the forefront of thinking on volunteering. This ground breaking work focussed on the impacts which volunteering can make to service users, the volunteer themselves, economically, socially and the development of shared cultural understanding **(KU 1 Critical overview; KU2 Detailed knowledge)**. I had then to assess how these applied to volunteering in palliative care, to select the resources from the toolkit which would be useful and appropriate to use in my own organisation.

Table 1: Evidence for Knowledge and Understanding

Learning Outcomes	Evidence
A critical overview of a subject / discipline, including critical understanding of the principal theories, principles and concepts. **(KU 1)**	Page 2 Introduction
	Page 4 Volunteers
	Page 4,5 Purpose of toolkit
	This paper Section 1 Knowledge and Understanding
A critical, detailed and often leading knowledge and understanding of the forefront of one or more specialisms. **(KU 2)**	Page 5 Purpose of toolkit
	This paper Section 1 Knowledge and Understanding

Knowledge and understanding that is generated through personal research or equivalent work which makes a significant contribution to the development of a subject or discipline **(KU 3)**	Page 18 Implications for future practice, Conclusions
	This paper Outcomes and Impact
	This paper Reflections on Research

2. Practice: Applied knowledge and understanding

The SCQF criteria under this heading require demonstration of the ability to:

- Use a significant range of principal skills, techniques, practices and materials associated with a subject/discipline. P1
- Use and enhance a range of complex skills, techniques, practices and materials at the forefront of one or more specialisms. P2
- Apply a range of standard and specialised research/ equivalent instruments and techniques of enquiry. P3
- Design and execute research, investigative or development projects to deal with new problems and issues P4
- Demonstrate originality and creativity in the development and application of new knowledge, understanding and practices. P5
- Practice in the context of new problems and circumstances P6

Having identified suitable methods, I then had to review and adapt these to make these suitable for use in a children's hospice, whilst ensuring that they still met the requirements for measuring the five areas of 'Capital' **(P1 Skills associated with discipline; P2 Range of complex skills; P3 Standard research instruments; P4 Design and execute research; P5 Demonstrate originality)**.

I also involved a team of team volunteers to undertake interviews with staff and families. These volunteers had previously been trained in interview skills and basic qualitative

research skills. Very few organisations have a team of volunteer trained in this way and consequently this was an innovative approach to research and resulted in an excellent response rate and further development of these volunteers' skills in researching **(P5Demonstrate originality; G3 Creative responses)**.

Table 2: Evidence for Practice: Applied knowledge and understanding

Learning Outcomes	Evidence
Use a significant range of principal skills, techniques, practices and materials associated with a subject/discipline. **(P1)**	Page 6 Methodology
	This Paper Section 2 Practice
Use and enhance a range of complex skills, techniques, practices and materials at the forefront of one or more specialisms. **(P2)**	Page 6 Methodology
	This Paper Section 2 Practice
Apply a range of standard and specialised research/ equivalent instruments and techniques of enquiry. ***(*P3)**	Page 6 Methodology
	This Paper Section 2 Practice
Design and execute research, investigative or development projects to deal with new problems and issues **(P4)**	Page 6 Methodology
	This Paper Section 2 Practice
Demonstrate originality and creativity in the development and application of new knowledge, understanding and practices. **(P5)**	Page 6 Methodology
	This Paper Section 2 Practice
	Page 17 Implications for future practice
	Page 12, 13 Findings: Staff, Families
Practice in the context of new problems and circumstances. **(P6)**	Page 17 Implications for future practice
	This paper Outcomes and Impact

3. Generic Cognitive Skills

The SCQF criteria under this heading require demonstration of the ability to:

- Apply a constant and integrated approach to critical analysis, evaluation and synthesis of new and complex ideas, information and issues. G1
- Identify, conceptualise and offer original and creative insights into new, complex and abstract ideas, information and issues. G2
- Develop creative and original responses to problems and issues G3
- Deal with very complex and/or new issues and make informed judgements in the absence of complete or inconsistent data/information. G4

The interviews and questionnaires produced a rich source of data both quantitative and qualitative. Responses to interview questions had been completed by volunteers under the question headings. I analysed the figures and calculated percentage responses to give context to the qualitative data for all groups: Volunteers, staff and families. I read through all the qualitative data, identified themes and coded the information by question. I undertook this process twice to verify accuracy of findings. This analysis was challenging as the concepts of the five areas of 'capital' being measured were complex to understand. I required to reference the definitions during the analysis to ensure that reporting was accurate **(G1 Integrated approach; G2 Range of complex skills; C4 Numerical data)**.

Table 3: Evidence for Generic Cognitive Skills

Learning Outcomes	Evidence
Apply a constant and integrated approach to critical analysis, evaluation and synthesis of new and complex ideas, information /issues. **(G1)**	This paper section3
Identify, conceptualise and offer original and creative insights into new, complex and abstract ideas,	This paper section 3
	Page 10, 11 Findings Volunteers, Staff
	Page 14, 16 Findings Families

information and issues. **(G2)**	
Develop creative and original responses to problems and issues **(G3)**	Page 6 Methodology
	This paper Outcomes and Impact
	Page 18 Conclusions
Deal with very complex and/or new issues and make informed judgements in the absence of complete or inconsistent data/information. **(G4)**	Page 6 Methodology

The findings identified new information which had, as far as I am aware, not been gathered in this way before in volunteering in palliative care, particularly in the area of children's hospices. This gave new insights into the volunteering experience, particularly the development of trust in others and in voluntary organisations and the impact of volunteers on staff and families. This information is referenced within the findings of the research.

4. Communication, ICT and numeracy skills

The SCQF criteria under this heading require demonstration of the ability to use a significant range of advanced and specialised skills as appropriate to a subject or discipline – for example

- Communicate at an appropriate level to a range of audiences and adapt communication to the context and purpose. C 1
- Communicate at the standard of published academic work and/or critical dialogue and review with peers and experts in other specialisms. C2
- Use a range of software to support and enhance work at this level and specify software requirements to enhance work. C3
- Critically evaluate numerical and graphical data. C4

The findings from this study have been communicated to a range of audiences. The report was sent to the Institute of Volunteering Research detailing the outcomes of the piloting of the materials. Feedback included comments on the applicability or otherwise of parts of the toolkit. Experience of the pilot and the findings were presented at the launch of the Toolkit by the Institute of Volunteering Research to an audience which included researchers and representatives from a diverse range of voluntary organisations. A paper was prepared and submitted to Voluntary Action, a peer reviewed journal and published in 2006.

An abstract was submitted, peer reviewed, and the paper accepted for presentation at the European Congress for Palliative Care in March 2005. This conference was attended by delegates drawn from across the Europe. Powerpoint Presentations were also made at Help the Hospices; the Children's Hospice UK Palliative Care Forum Conference (Appendix 3:3) attended by professionals from across the UK and the Scottish Association for Volunteer Managers Conference attended by volunteer managers from a range of voluntary and statutory organisations across Scotland. **(C1 Communicate to range of audiences; C2 Standard of published work)**

Table 4: Evidence for Communication, ICT and numeracy skills

Learning Outcomes	Evidence
Communicate at an appropriate level to a range of audiences and adapt communication to the context and purpose. **(C1)**	This paper Section 4
Communicate at the standard of published academic work and/or critical dialogue and review with peers and experts in other specialisms. **(C2)**	This paper Section 4
Use a range of software to support and enhance work at this level and	Appendix 3:3

specify software requirements to enhance work. **(C3)**	
Critically evaluate numerical and graphical data. **(C4)**	This paper section 3

5. Autonomy, accountability and working with others

The SCQF criteria under this heading require demonstration of the ability to:

- Exercise a high level of autonomy and initiative in professional and equivalent activities. A 1
- Take full responsibility for own work and/significant responsibility for the work of others. A 2
- Demonstrate leadership and/or originality in tackling and solving problems and issues. A3
- Work in ways which are reflective, self-critical and based on research evidence. A4
- Deal with complex ethical and professional issues. A5
- Make informed judgements on new and emerging issues not addressed by current professional and/or ethical codes or practices. A6

Table 5: Evidence for Autonomy, accountability and working with others

Learning Outcomes	Evidence
Exercise a high level of autonomy and initiative in professional and equivalent activities. A 1	This paper Reflections on Research
Take full responsibility for own work and/significant responsibility for the work of others. A2	This paper Reflections on Research

Demonstrate leadership and/or originality in tackling and solving problems and issues. A3	This paper Reflections on Research
Work in ways which are reflective, self-critical and based on research evidence. A4	This paper Reflections on Research
Deal with complex ethical and professional issues. A5	Page 7: Ethical Considerations
Make informed judgements on new and emerging issues not addressed by current professional and/or ethical codes or practices. A6	Page 18 Implications for future practice
	Page 19 Conclusions
	Page 19 Conclusions
	This paper Outcomes and Impact

6. Outcomes and Impact

There have been a number of outcomes arising from this study.

Since the research report was presented, a leaflet for families about volunteers was developed to reassure families about vetting and to raise awareness of their role in the organisation. The information from the leaflet has since been incorporated into a handbook of information for families. The extract is attached as Appendix 3:4 **(P6 Context of new problems; KU3 Knowledge generated through personal research; A6 Informed judgements)**.

The role of volunteers in home care has been piloted with our Inverness based CHAS at Home team. Volunteers have been recruited to help with administration, driving, activities, complementary therapies and ironing **(KU3 Knowledge generated through personal research; P6 Context of new problems; G3 Complex issues; A6 Informed judgements)**.

An active and dynamic young volunteer programme has been active in CHAS for a number of years. 91 volunteers aged 15 years and over from local high schools are involved in both hospices. They help at mealtimes, in housekeeping, fundraising and in befriending the young adults who use our hospice services **(KU3 Knowledge generated through personal research; P6 Context of new problems; G3 Complex issues; A6 Informed judgements)**.

It is clear that the findings from in piloting the toolkit led to the improvement and development of the voluntary service in CHAS. **(P6 Context of new problems)**

7. Reflections on Research

I embarked on this project a number of years ago and I found it both rewarding and exciting to be able to analyse and apply a new resource with a view to practice development in my organisation and in palliative care more widely. It was also a great compliment for me to be asked to pilot such a new resource and CHAS was approached because of the recognition of our innovation and creativity in volunteering in paediatric palliative care which were considered to be at the forefront of practice development **(A1 High level of autonomy; A3 Demonstrate leadership; A5 Complex ethical issues)**. **It was really motivating to have my work recognised in this way and to be the only organisation in Scotland to be approached.**

One of the strengths of the study was the involvement of ten volunteers who had previous experience of interviewing as part of an evaluation study. I chose to work with volunteers to implement the toolkit as previous experience with this group had suggested that their

involvement produced a high response rate and a high quality of information as staff and families had demonstrated a high level of trust and were open and honest, especially when reporting negative information **(A3 Demonstrate leadership)**. When this group had been involved in previous small scale studies response rates were in the region of 90%.

All, however, had limited experience of research either qualitative or quantitative and my responsibility therefore was to analyse the toolkit and identify the appropriate components, adapt the questions and language to make them appropriate for CHAS. I also required to brief the team and support them through the process to ensure that all stages that were carried out to the highest standard **(A1 High level of autonomy; A2 Responsibility for work of others; A3 Demonstrate leadership)**.

One of the limitations of the research process was that I was using a prescribed toolkit. Whilst well thought out and allowing for a small range of approaches, the pre-prepared questionnaires had been drafted for use in any organisation and some questions were not suitable for use in a hospice setting. For example, one of the questions for service users was "What are your hopes for the future?" In working with families facing the death of their child, this question did not seem appropriate. The use of pre-prepared materials also restricted the areas which we could explore which reduced the effectiveness of the findings for the organisation. The study was also limited by the lack of any literature review and the use of only one method of data collection. **(A4 Work in ways which are self-critical)**.

The report lacks a critical analysis of relevant literature which would have helped to set the study and the toolkit in the wider volunteering context. The referencing is inconsistent in terms of dates and publishers.

I learned much from the process, particularly about capacity building within organisations and the contribution which volunteers can make to this. I developed my critical analysis skills in assessing the content of the toolkit and considering the applicability and appropriateness of the data collection methods. Having previously used only qualitative questionnaires, I learned the value of the use of multiple choice answers and how to

undertake some basic quantitative analysis **(KU 3 Knowledge generated through personal research; A4 Work in ways which are self-critical)**.

Were I to undertake such a project again I would plan to involve the volunteers more in the planning of the project and also in the analysis of data to minimise any bias that I, as a practitioner researcher, would inevitably have brought to the process. I would also want to develop further my quantitative research skills in order to make better use of the quantitative data from such a study. I would also increase the sample sizes to strengthen the applicability of the findings.

We are about to evaluate the impact and experiences of the volunteers in our organisation this year and I will consider using the Impact Assessment Toolkit once again but would want to apply my learning gained during the pilot study. Therefore, I would again want to use volunteers as this was a strength of the project, but I would increase the sample sizes in all areas; develop the questionnaires to allow for the collections of additional qualitative data; analyse the data collectively and use additional data collection methods **(KU3 Knowledge generated through personal research)**. It will be interesting to re-visit the Toolkit some years on and to review it for use again on a wider scale and be able to implement some of my suggestions for improvement.

References

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2. Scottish Curriculum and Qualifications Framework (2003) Level 12 doctoral level criteria. Retrieved on 10 October 2009 from www.scqf.org.uk.

APEL CLAIM Part 3 Appendix 1

OTHER PEOPLE'S TIME

A Study of the Impact of Volunteers in a Children's Hospice

Abstract

The Children's Hospice Association Scotland was invited to take part in the pilot of the Institute of Volunteering Research's Volunteering Impact Assessment Toolkit. This study explored the impact of volunteering on families, staff, the volunteers themselves and on Rachel House children's hospice as a whole. Using interviews based on questionnaires provided in the toolkit, trained volunteers gathered data from staff and families. Volunteers responded to postal questionnaires. The findings clearly indicated that volunteering had a significant and positive impact on families, offering additional support, extending services and reducing isolation. They also impacted significantly on staff morale and development, whilst increasing their own social networks and personal growth. If the findings from this study are replicated, volunteers clearly have a significant role to play in children's hospices.

Acknowledgements

Thank you to families, staff, volunteers and volunteer co-researchers who took part in this study.

Introduction

The Children's Hospice Association Scotland (CHAS) was set up in 1992 to provide children's hospice services in Scotland. CHAS offers palliative respite care, emergency care, home care, and terminal care to children with a life threatening or life limiting condition. This care extends to the whole family from the point of diagnosis and into bereavement. Care is provided through a triangle of services: two children's hospices - Rachel House in Kinross in the East of Scotland, Robin House in Balloch in the West of Scotland and also Rachel House at Home offering home care support to families in the North of Scotland. Fewer than 11% of children using the service have cancer, the majority of children having very complex life limiting conditions. The conditions fall into several categories as defined by the Association of Children's Hospices:

- life threatening conditions for which curative treatment may be feasible but can fail
- conditions where premature death is possible or inevitable
- progressive conditions without the option of curative treatment
- severe neurological disability which may cause weakness and susceptibility to health complications **(KU1 Critical overview)**

In CHAS care is given to families by a multidisciplinary team of staff, which includes volunteers of all ages, backgrounds and experience.

Volunteers

CHAS is very committed to the involvement of volunteers in every area of work. Currently there are over 780 volunteers spread throughout Scotland in 47 different roles. They are involved in our national network of fundraising volunteers, four CHAS fundraising offices, head office, three shops and all hospice services. Volunteers in the hospices are involved in the office, kitchen, housekeeping, garden, driving, activities with the children, babysitting, bereavement support, complementary therapies, staff support, volunteer administration, training and research. Their contribution throughout CHAS during 2005 was over 73,000 hours, the economic value of which is worth £881,000 to the organisation **(KU1 Critical overview)**.

During an external evaluation of the voluntary service in 2003 by Volunteer Development Scotland, ten volunteers were trained as co-researchers, playing a key role in the gathering of information. These volunteers were subsequently involved with the piloting of the Institute of Volunteering Research Toolkit.

Purpose of Toolkit

Demonstrating the value of the contribution which volunteers make to organisations has always been a challenge. It has been possible to measure numbers, hours donated and the economic value, but these fail to recognise the significant commitment of skills, life experience and the difference which volunteers make to individuals, organisations and to themselves **(KU1 Critical overview)**. The Toolkit, developed by the Institute of Volunteering Research, offers

organisations a much needed method of evaluating the impact of volunteers by measuring five areas: Physical, Human, Economic, Social and Cultural Capital. These are defined in the Toolkit as:

- "Physical Capital: the concrete product or output gained by the recipient
- Human Capital: the acquisition of skills and personal development
- Economic Capital: the specifically financial and economic result from volunteering
- Social Capital: …to capture social impacts
- Cultural Capital: refers to assets such as a shared sense of cultural and religious identity including language and heritage"

Institute of Volunteering Research (2004) **(KU2 Detailed knowledge)**.

CHAS was approached, through Help the Hospices in 2004, to be part of the pilot of the Toolkit as the Institute of Volunteering Research was keen to have organisations from different sectors involved in assessing the efficacy of the materials. This was an excellent opportunity for CHAS to gather complementary information, which would build upon the data gathered in the external evaluation, to give a comprehensive overview of the impact of volunteering in the organisation.

Methodology

Although the Toolkit enables organisations to measure the impact of volunteering across the organisation, involving all stakeholders and including the local community, CHAS chose to focus only Rachel House, its first and longest established children's hospice. Families, staff and volunteers were identified as

the key stakeholders for the purpose of this project.**(P1 Skills associated with discipline)**.

Telephone interviews, based on the Toolkit questionnaires, were held with staff and families, whilst postal questionnaires were sent to volunteers. Interviews were carried out by ten volunteer co-researchers and ensured a high response rate in both groups. Staff were divided into two distinct groups: those working alongside volunteers and those with a supervisory role. Staff in the first group were interviewed using the framework of the core questionnaires whilst interviewers used the in depth questions with the second group **(P1 Skills associated with discipline; P2 Range of complex skills; P3 Standard research instruments; P4 Design and execute research)**.

The sample size of the family group was small, with only 12 families being identified by care staff. It was extremely important to be sensitive to the situations of families at the time of the study and this resulted in the small number involved **(P4 Design and execute research)**. Staff and volunteer samples were randomly selected and comprised 20 in each group **(P2 Range of complex skills; P3 Standard research instruments)**.

The questionnaires were adapted slightly to suit the environment and culture of CHAS. Questions regarding the future were not deemed suitable for families and were removed. Four questions were added to gain an added insight into families' views of volunteers, and also for the future development of the voluntary service,

as this was the first time families had been asked about their experiences of volunteers **((P1 Skills associated with discipline; P2 Range of complex skills; P3 Standard research instruments; P4 Design and execute research; G3 Creative responses; G4 Complex issues)**.

Ethical Considerations

Permission was sought from the CHAS Chief Executive and Head of Care at Rachel House before embarking on the study. All participants were invited to take part and only those who indicated their willingness were involved. Respondents were able to opt out of the study at any time and completed responses remained anonymous to ensure confidentiality. Great sensitivity was required in dealing with families in recognising the considerable stress and unpredictability with which they lived. The Head of Care was therefore responsible for identifying suitable families and the project team recognised that families might choose to withdraw at any time **(A5 Complex ethical issues)**.

Findings

Volunteers

The volunteer questionnaire, of the three, was the one which elicited the broadest spread of responses and therefore trends, in some areas, were difficult to identify. A total of 20 questionnaires were sent out, of which 16 were returned, giving a response rate of 80%. The findings from this group were very positive about their experiences in Rachel House and supported the findings from the external evaluation.

In the main, volunteers felt that they had good access to training with 75% reporting that the courses were of interest, of a high quality and were relevant to their roles. Only 20% of respondents, however, were interested in accreditation resulting from training. This may reflect the age of the sample group, of which the majority of the respondents were retired. It should be noted, however, that there are some roles for which no course is required beyond introductory training e.g. housekeeping.

There was a mixed response to the questions on social events. The majority of respondents (81%) were positive about social events in terms of frequency, convenience and enjoyment, however 31% indicated that these were not well attended. As there is a high degree of social contact built in to the volunteering roles in most areas, this may have an impact on numbers attending events.

Volunteers reported very positively on their experiences of management, reporting that in the main their skills were well used, they knew what was expected of them, volunteering was well organised and that good support was offered. They also indicated a high level of satisfaction with the recognition that their volunteering received from the organisation.

Three instances, however gave rise to concern – 18% felt that their skills were not well utilised; 6% would like volunteering to be better organised and 12% felt that they were taken for granted.

Volunteers reported a positive impact on their personal development from volunteering, although levels of confidence, sense of self esteem and motivation was reported in 39% of cases as staying the same. One respondent commented that “because you are helping people, you feel better about yourself.”

Although a small percentage of volunteers reported an increase in skills development, many reported this as staying the same. Some indicated that they valued “being able to use their skills and experience of life in a different way.” Given that the feedback on training experiences in a previous evaluation were extremely positive about opportunities, it may be that this reflects very much our recruitment methods in trying to involve people with the relevant skills to the roles. Once again this may also reflect the stage in life of those within the sample. The majority of volunteers (75 %) also reported that both their physical health, mental health and wellbeing had stayed the same.

In exploring the economic impact on respondents of their volunteering, only one reported being out of pocket for voluntary work and this was by choice, in that they chose not to claim any out of pocket expenses. The majority of volunteers did not feel that the increase in earning power and employability was relevant to them and this may support the theory that this is due to the overall age group within this sample. It would be interesting to explore this aspect with younger volunteers.

The social aspects of volunteering were positively reported, with 84% of respondents indicating that this had increased friendships, contacts and social

networks. This is clearly very important to volunteers and a number of responses indicated that “meeting new people from all walks of life” was one of the key benefits of volunteering. Those who reported that networks and contacts had not increased; may reflect the fact that some volunteers live very locally and may already have established social networks.

Over half of respondents reported that volunteering had helped them to develop an increased trust in others, a feeling of inclusion, willingness to look out for other people and to try new things. The largest impact, however, is reported as an increased trust in voluntary organisations **(G2 Original insights)**. Volunteering in Rachel House seemed to have little impact on volunteers’ participation in local activities. This perhaps reflects that the hospice is very much a community in itself and is very much part of the wider local area.

Feedback indicated that volunteers’ sense of cultural identity had remained the same in 63% of cases. This is unsurprising given that the hospice is based predominantly in an area with little ethnic diversity and that the number of families from ethnic backgrounds using the hospice were small.

All participants indicated that they would recommend volunteering to other people, with the sense of giving back “as a repayment for what I have got out of life,” feeling part of a team and feeling valued highlighted as the main benefits. One respondent emphasised the significance of appreciation by commenting that “every time I volunteer, one of the organisers says ‘thank you’ – this is so important.”

Volunteering was reported as having a positive effect on respondents' outlook on life, with 69% indicating that things were changing for the better. This was attributed to volunteers developing a different perspective on life, recognising their own fortunate circumstances and a sense of fulfilment from voluntary work. Volunteers had a clear sense of being an integral part of the hospice team and feedback from staff clearly supported this view. **(Original insights)**.

Staff

The response rate from staff was 95% with 19 out of 20 interviews taking place. All staff reported high levels of satisfaction with the quality, quantity and degree of innovation of the voluntary service, reporting positively on the impact on both their own development and that of the organisation. Volunteers were also valued for the special qualities which they brought to the organisation and their flexibility and fresh ideas were highlighted. However 38% felt that the standard of volunteers work could be improved.

Reporting on the economic impact on the organisation, 100% of respondents recognised the volunteers' significant contribution to CHAS's income and to the value of the work undertaken. Staff were also of the opinion that volunteers contributed to the creation of new jobs within the organisation **(KU3 Knowledge gained through personal research ; G2 Original insights)**.

The data indicated that staff felt that volunteers contributed significantly to recruiting and retaining quality volunteers, with 83% indicating that volunteers

greatly enhanced the organisation's reputation. However, in the view of staff, volunteers had little to contribute to the recruitment and retention of paid staff.

The majority respondents (83%) reported that volunteers contributed to a diverse and open organisational culture offering culturally appropriate services for the local community. This last point is surprising, as neither the volunteers, nor the hospice community is culturally diverse, mainly due to the demographics of the local area as mentioned previously. The definitions of 'diverse' and 'culture' may, therefore, have been interpreted as age, background, gender and ethos in relation to volunteers.

Staff feedback was very positive about the management of volunteers within the hospice, highlighting good training and support provision. These supported findings from the volunteers relating to their experiences of management. Only 33% of the staff group identified a need for additional resources to be spent in this area. The impact of the value of volunteers was rated highly in all areas including: effective service providers, and as partners and co-workers. Volunteers were recognised as a resource in helping to reach potential hospice users. Staff also highlighted the importance of volunteers to the sustainability of the organisation and to enhancing the organisation's reputation in the local community.

Data indicated an interesting divergence of views with 38% of respondents reporting that the organisation did not have sufficient volunteer input whilst 15%

indicated that CHAS was over-reliant on volunteers. Some staff (31%) were unhappy with the role and influence of volunteers. These areas warrant further investigation to explore reasons behind the differing views.

There was, however, consensus around the impact of volunteers on personal development: "volunteers have helped me personally to develop and promote new skills acquired from interactions and communications between them and myself" **(P5 Development of new knowledge; G2Original insights)**. Most staff also cited volunteers as making their jobs easier, enabling them to undertake work which they would otherwise not have time for and contributing to their awareness and thinking. Respondents did not feel that volunteers took up too much time, nor did they distract staff. The complementary roles of staff and volunteers were valued and the positive effect on staff morale was also highlighted.

It would seem therefore volunteers have a key role to play in staff development, the value of which, may not always be recognised by organisations **(P5 Development of new knowledge; G2Original insights)**.One particular area gave some cause for concern as staff did not seem to recognise the role of volunteers as trustees. This may be due lack of knowledge and understanding of the role and the function of the CHAS Board and lack of recognition of their volunteer status. Clearly, this must be addressed.

It is apparent from the responses that staff valued the significant and diverse impact of volunteers and their importance both to staff as individuals and to the

organisation as a whole. One respondent stated that “CHAS would not be able to do all that it does without them.” “Volunteers have an immense impact on our staff ability to fulfil potential in a positive manner.” The views of staff reassuringly support the experiences of the volunteers within CHAS and are congruent with those of the families.

Families

Although previous anecdotal evidence from families had given an indication of their views on volunteers, this was the first time that families had been formally approached **(P5Development of new knowledge)**. Twelve interviews were arranged with 11 actually taking place giving a response rate of 92%. Feedback from this group was the most positive of all and clearly the impact of volunteers on families is very significant.

Families had accessed a range of volunteer support, including driving, complementary therapies and babysitting. They also highlighted the value of the volunteer involvement in the kitchen, housekeeping, gardening, activities with siblings and fundraising. Some reported the difficulty in separating volunteers from staff, but identified this as ‘a strength’ of the hospice. This supports staff and volunteer views from the previous external evaluation. This lack of differentiation, however, makes it difficult to attribute all responses from the interviews to volunteers alone.

All families were satisfied with the amount of help received, in addition to the quality and innovation of services. The beneficial economic effect on families was also rated highly. One parent reflected "we don't have the budget for the wonderful things we have managed to achieve through the help and skills of the volunteers." A surprising finding was the number of families (73%) who reported positively that volunteers had helped them to increase their social links. Respondents highlighted the benefits of developing new friendships, contacts and identified an increased sense of trust in others. Conversely, volunteers made no particular impact in helping families to engage in activities local to them. This may be due to the significant problems faced by families in caring for a child with a life limiting condition **(G2 Original insights)**.

Many positive aspects of volunteer involvement were identified by families, including their impartiality and the additional support which they provided. Other areas highly valued by families were cited as the variety of services offered, particularly complementary therapies and hairdressing, and the opportunity to spend time talking to hospice volunteers. Families very much valued engaging with the shop volunteers as additional listening ear. Volunteers also had a key role to play in assisting families to get out and about, an activity which, for most hospice users, can be almost impossible without a great deal of help and support.

Families identified very few negative aspects of volunteer involvement. Those reported included a lack of necessary experience and information relating to affected children, and a lack of consistency in the numbers available. Although

volunteer turnover rates in Rachel House are very low, the lack of regularity is a small, but increasing problem. As people have less time to offer, it requires an increased number of volunteers to provide the same level of service as in previous years.

Respondents found volunteers to be pleasant, helpful, caring and understanding as evidenced by two respondents: “volunteers provide a wonderful service and ease the situation considerably” and “any contact is superb.”

All families reported that the work of CHAS was enhanced by volunteers, highlighting that the organisation could not do all that it does without volunteer support. This is strongly convergent with the views of staff. It was felt that the involvement of volunteers extended the range of support available to families. Respondents also identified that volunteers “allow the care team members to concentrate on their special work” and thereby providing important support to paid staff. Encouragingly, this finding is strongly endorsed by the responses from the staff group.

Families were asked if they saw any difference between the approach of paid staff and volunteers. Respondents identified that volunteers had the same desire to help and care for the children as the paid staff team. The main difference identified was in relation to the care of affected children, recognising that staff had more skills and responsibility in this area. One parent indicated that they could not trust a volunteer to undertake a care role with an affected child. This is perhaps

unsurprising, as it can be very difficult for parents to build up trust with staff who care for their child as many children have extremely complex medical needs. Initial concern over the vetting of volunteers was raised by one respondent, which has highlighted a gap in our information provision to families. Conversely, one response indicated a higher level of trust in volunteers "because of the time they give you". Volunteers were also identified as being more relaxed than paid staff, which perhaps reflects the fact that volunteers have the opportunity to contribute their time and skills in a different and complementary way to that of paid staff **(G2Original insights)**.

When asked what additional support volunteers could offer, 3 respondents indicated a wish to see volunteers involved in home care. Other suggestions included involving additional young volunteers who would bring benefit children and their siblings.

Implications for Future Practice

There were a number if implications for future practice in CHAS arising from the findings. The following areas for action were identified:

- a review of how volunteers skills are utilised to ensure these are engaged effectively
- a review of the way in which volunteers are valued in order to address concerns raised

- raising awareness within the organisation of the role and volunteer status of the CHAS Board
- the development of a leaflet for families about volunteers and their role in CHAS to reassure families about vetting and to raise awareness of their roles.
- an assessment of the opportunities for involving volunteers in home care
- an assessment of possibilities for the development of the young volunteer programme **(P5 Demonstrate creativity; P6 Practice in the context of new circumstances)**.

These areas have all been addressed and a pilot project involving volunteers in home care has recently begun. A new team of young volunteer befrienders has also been introduced to provide additional support for adolescent hospice users. It will, however, be important to continue to monitor the effectiveness of the response to all the issues which arose from the project **(P6 Practice in the context of new circumstances)**.

The findings from this study may also however have wider implications for children's hospices, which may be considering whether or not to engage with volunteers, and the appropriateness of their involvement with children and families. Through volunteering, our volunteers developed and increased belief in voluntary organisations, which if replicated within other (organisations, clearly has significant

implications for the voluntary sector (**KU 3 Knowledge gained through personal research; A6 Informed judgements)**.

Conclusions

The evidence clearly indicates that volunteering has an important and positive impact on the families, staff, the organisation as a whole, and on the volunteers themselves. The greatest impact was reported by families and staff. Whilst engaged in volunteering, people played a key part play in reducing families' isolation and increasing their own network of social contacts. Volunteers demonstrated their value in helping people to develop trust in others. In addition to considering how to engage volunteers to maximise these outcomes, consideration must also be given to the significant potential of their contribution to staff development and morale. Drawing on the data from this study, volunteers clearly have an indispensable role to play in children's hospices and the argument for their involvement from all parties is overwhelming **(KU3 Knowledge gained through personal research; G3 Creative responses; A6 Informed judgement)**.

With this in mind, our challenge in CHAS for the future will be to maintain, improve and develop the level of service which we have at present, within a rapidly changing demographic environment. The greatest challenge of all, however, is to sustain a service based on that most precious and increasingly scarce resource – other people's time.

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1. Institute of Volunteering Research, (2004), Volunteering Impact Assessment Toolkit

2. Association of Children's Hospices "What is a children's hospice?" ACH, Bristol

APEL CLAIM Part 3 **Appendix 3.2**

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Children's Hospice Association Scotland
Sharing the Caring

APEL Claim Part 4 Appendix 3:3
Children's Hospice UK Conference
May 2006

OTHER PEOPLE"S TIME

ROS SCOTT HEAD OF VOLUNTARY SERVICES

BACKGROUND TO STUDY

- CHAS
  - Triangle of Care
  - Volunteers
- Pilot for Institute of Volunteering Research

Ros Scott Head of Voluntary Services CHAS

PURPOSE OF TOOLKIT

- Skills and Personal Development
- Financial and economic impacts
- Building relationships and trust
- Shared sense of cultural identity

Ros Scott Head of Voluntary Services CHAS

METHODS USED

- Toolkit
- Identifying all those affected
- Adapting for CHAS
- Volunteer Co-researchers
- Questionnaires and interview

Ros Scott Head of Voluntary Services CHAS

FINDINGS FROM FAMILIES

- Difficult to differentiate –excellent!
- 100% satisfied and would recommend
- 100% -CHAS' s work enhanced
- 64% - access increased range of services
- 73% - help to develop trust /social networks
- Request for volunteer support at home

Ros Scott Head of Voluntary Services CHAS

BENEFIT TO FAMILIES

- Volunteers impartial
- Just being there – everyday activities
- Alternative support and friendship
- Time to talk and listen
- Nothing is too much trouble
- Importance of shops and fundraising volunteers
- Vital to CHAS

Ros Scott Head of Voluntary Services CHAS

DISADVANTAGES

- May lack necessary experience / information
- Lack of consistency in numbers available
- Initial concerns over vetting
- 56% - none

Ros Scott Head of Voluntary Services CHAS

FINDINGS FROM STAFF

- 100% - v satisfied with quality, quantity, innovation
- 100% - positive economic impact
- 100% - positive impact on recruitment & retention
- 83% - enhanced reputation

Ros Scott Head of Voluntary Services CHAS

MORE FINDINGS FROM STAFF

- 83% - diverse culture - inclusive and welcoming
- Effectiveness - highly rated
  - Help to fulfil staff potential
  - Contribute to professional development
  - Motivate staff
  - Development of CHAS and sustainability
- Board not recognised as volunteers

Ros Scott Head of Voluntary Services CHAS

OUTCOMES

- Raise awareness of role status of CHAS Board
- Pilot of volunteers in home care
- Leaflet for families
  - How volunteers are recruited and vetted
  - Raise awareness of roles

Ros Scott Head of Voluntary Services CHAS

"Volunteers have helped me personally to develop and share new skills acquired from interaction and communication between them and myself"

Staff member – Rachel House Care Team

Ros Scott Head of Voluntary Services CHAS

Appendix 3:4

Extract on the role of volunteers taken from handbook of information for families using Rachel House children's hospice.

Our Volunteers

Cherry Allan and Caroline Marshall are our Volunteer Managers who between them look after the small army of volunteers who give of their time and effort in helping to run Rachel House. If you are looking to book any of the services offered by volunteers, such as complementary therapy or babysitting, please speak to a member of the care team who will liaise with Cherry or Caroline. In the course of a normal day one or the other can be found either in their office or moving around the house catching up with volunteers. Please fell free to chat to either of them if you have any questions about volunteering issues.

CHAS has a dedicated and enthusiastic team of volunteers who help us, not just in Rachel House, but throughout the whole of the CHAS organisation. Within Rachel House our valued team of volunteers help out in a variety of areas such as the kitchen, housekeeping, reception and admin, driving, gardening, activities, complementary therapy and befriending.

Volunteers within the hospice are recruited and trained in accordance with current guidance and legislation. Within the bounds of their volunteer role, they are there to help you in any way possible.

7

APEL CLAIM Part 4 **Rosalind Scott**

Matriculation No: 030015787

Volunteers in Hospice and Palliative Care

Contents

APEL CLAIM Part 4 **Rosalind Scott**
Matriculation No: 030015787

Claims for the book 'Volunteers in Hospice and Palliative Care'

Introduction

The purpose of this APEL claim is to demonstrate that the writing, research and publication evidenced in this paper was undertaken at doctoral level. This paper reports the work undertaken in editing the second edition of the book "Volunteers in Hospice and Palliative Care" published in September 2009 by Oxford University Press (www.oup.com/uk/medicine). (Appendix 4:1).

Structure of Claim Document

This paper provides evidence under the five headings of the Scottish Curriculum and Qualifications Framework Level 12 doctoral level criteria (SCQF, 2003) (Appendix 4:2):

- Knowledge and Understanding
- Practice: Applied knowledge and understanding
- Generic Cognitive Skills
- Communication, ICT and numeracy skills
- Autonomy, accountability and working with others

Under each of the headings I will evidence the work undertaken for the project against the characteristic generic learning outcomes and my learning from it. As these are intended to give a general overview of learning outcomes, I will endeavour to match these as closely as possible, recognising however that not all evidence will match exactly in one claim.

Background to Project

I was approached by Oxford University Press (OUP) in 2007 and asked to consider editing the revised edition of this book which had been at the top of their 'best sellers' in the medical books division (Appendix 4:3). I was a contributing author to this book and had written a chapter on "Volunteers in Children's Hospice" The editor of the first edition had decided not to continue in this role as he had found the editing of the first edition very onerous because of the lack of writing experience of many of the chapter authors. I had met the previous editor at a palliative care conference and had indicated to him my concern that the first edition of the book was very out of date and that it really needed to be revised or withdrawn. He mentioned that he would contact the commissioning editor at OUP and ask her to get in touch with me so that I could discuss my concerns with her.

The first edition was published in 2002 and was, as far as I am aware the first text which focussed on volunteering in hospice and palliative care settings. The book comprised 14 chapters including a foreword by Dame Cicely Saunders who was a very highly respected professional in the field and known throughout the world as the founder of the modern hospice movement.

The chapters were commissioned as 'stand alone' pieces of work and most were written by practising voluntary services managers. The book covered topics ranging from: the management role of the Voluntary Services Manager, recruitment, selection, training and support of volunteers to models of volunteer involvement in a range of settings out with UK (Canada, Australia and South Africa). Other chapters covered the role of volunteers in children's hospices; bereavement services; professionals working as volunteers, legal issues and ethical issues.

As a first time editor, I decided to co-edit with a colleague. I felt it important that my co-editor had a background in the wider voluntary sector to bring a broader dimension to the book. I believed that the partnership would be strengthened by a colleague with a breadth of experience in writing for publication. I initially approached a well-respected colleague, the then Director of the Institute of Volunteering Research with whom I had previously

worked on a number of projects. His workload at that time did not permit him to take on an editorial role and he recommended a colleague at the Institute who edited their journal 'Voluntary Action' with whom I had also previously worked on joint projects with Help the Hospices.

This paper documents the process undertaken from the development of the proposal to the publication and launch of the book.

My Role as an Editor

The Proposal

In order for my co-editor and I to develop a proposal for the book (Appendix 4:4), the starting point was to review and analyse critically the first edition identifying chapters which needed to be removed, those which needed revised and the intended content of new inclusions. The criteria for analysis included:

- the relevance of the information to current practice
- accuracy of information
- information which was out of date
- gaps in subject topics and information
- quality of writing
- readability and flow

As the book was aimed at an international audience with authors from UK, Australia, Canada and South Africa; this required a critical overview of volunteering in palliative care, in adult and children's settings, in a range of different countries **(KU 1 Critical overview).** It was important also to analyse the principles and theories contained in the first edition in order to assess whether these met with current theoretical perspectives, current literature and best practice. In this way it was possible to identify clearly which parts of the book were out of date, which could be updated through editing and which chapters required to be removed and replaced. It was also important to consider new theories, practices and approaches and consider how these might be introduced. In doing

this I drew heavily from my own experience as a practitioner since 1991and that of other practitioners in the field of volunteer management through discussions at volunteer managers' fora. **(KU 2 Leading knowledge; P2 Range of complex skills)**.

Whilst the very existence of the first edition of the book was a significant achievement and milestone in the progress of volunteer management in palliative care, as previously mentioned, most chapters had been contributed by practising voluntary services managers. These authors had varying levels of experience of writing and publication. One of the weaknesses of the book, therefore, was the variation in the quality of writing. There was also a lack of flow and linking between chapters **(G1 Critical analysis)**.

With a view to the development of a second edition, it was therefore necessary to assess the quality of the writing and consider whether these chapters could be further edited to improve their quality or whether the needs of the reader would be better served by the introduction of more experienced authors.

Following this analysis and review, the proposal was written, identifying chapters to be removed, what revisions would be made and which additional subjects would be introduced in new chapters. This was then submitted for review by the editorial panel as were the curriculum vitae of myself and my co-editor before we were accepted by Oxford University Press.

Two chapters were identified for a complete re-write with new authors, one for a complete re-write with the same author, one chapter for removal and 3 new chapters were proposed. These new chapters included: The Landscape of Volunteering to set palliative care volunteering in context; Quality Standards to contribute to knowledge of best practice in management and encourage managers to see these as integral to best practice; Neighbourhood Networks in Palliative Care, a chapter of innovative volunteering in India. Three chapters were rewritten: Ethics and Volunteering (new authors), Volunteers and the Law (new author) and Volunteers in Children's Hospices (one of my chapters). I deal with my role as an author in more detail in APEL Claim Part 5.

Identifying Authors

Once the proposal had been accepted it was important to begin the work of identifying and contacting authors who had contributed to the first edition to advise them of the proposed new edition. In some cases this involved advising authors that their chapters were being withdrawn. This was a challenging task. I made contact with both authors by email as we had no telephone details for them. I considered my approach carefully and approached the situation with great tact. I described my role and the proposal to revise the book and explained that as practice had developed considerably, sadly the chapters concerned had become dated and it was with regret that they would be withdrawn from the book.

The review of the first edition had identified one of these two chapters, Legal Issues for Voluntary Services Managers as being poorly written, structured and confusing to read **(G1 Critical analysis)**. It is a vital and very complex subject and it was important for this to be written by an author with a breadth and depth of current knowledge and expertise in this area. As the previous author had retired from work a number of years previously, she understood completely that there was a need to update the chapter and therefore to find a new author. Both authors were very gracious and took the news well.

Significant detective work was involved at this stage as a number of previous authors had retired or left the field. It proved impossible to contact all authors and advice was sought from Oxford University Press on how to proceed. We were advised by OUP that because they held the copyright for the book, it would still be possible to edit chapters from authors who who were not contactable.

One of the most exciting aspects of revising and editing a multi-author text is the opportunity to invite new authors to bring fresh perspectives and creative ideas to catch the imagination of readers and to inspire developments in their workplaces. This was therefore one of the criteria in identifying new authors. Another was to improve the quality of writing in some of the weaker chapters which had been withdrawn. It was therefore decided to try to approach people who had previously written and published key work in the field to invite them to contribute to this new revised edition. This would also contribute not only to

the quality but to the credibility of the book. We were fortunate to attract three new, high profile, well respected authors from UK, USA and India to contribute chapters on Legal Issues, Ethics and Neighbourhood Networks in Palliative Care.

Developing Practice

Whilst there are a number of books on volunteer management, as far as I am aware this is the only text which deals exclusively with volunteers in hospice and palliative care. The book had an international audience, was also a recommended text for a number courses and very much viewed as an authoritative text for both volunteer managers in palliative care and their organisations **(C3 published academic work)**. The content therefore had to be at the forefront of practice in volunteering and volunteer management in hospice and palliative care and I, as an editor and author, had to build and develop my own knowledge to this level to ensure that the book reflected this **(P2 forefront of specialisms)**. In order to be able to edit the text effectively, I was required to bring together my research skills gained through previous studies, literature review skills and my own experience as a practitioner in volunteer management in order to further develop my own knowledge and understanding
(P 1 range of principal skills techniques and practices, P3 standard and specialised research techniques). The application of research skills provided a framework and methodology for the review of the book. I approached the task using a qualitative case study method. In defining this, Patton (1987, 149) states that 'regardless of the unit of analysis, a qualitative case study seeks to describe that unit in depth, in detail, in context and holistically'. The 'unit of analysis' in this case was the first edition of the book. I also applied the documentary method of data analysis. This involved the stages whereby, the main topics, impressions, convergences and divergences were noted (Sarantakos, 2005) and provided a useful approach to analysing the text.

The skills previously developed in undertaking literature review were also valuable in approaching the review of the book, analysing the structure and content of chapters, comparing this to current literature and practice from my reading and practitioner

experience in the field of palliative care volunteering **(P3 Range of techniques of enquiry).** From this I was able to identify gaps in information and to assess whether the chapter could be updated with new information, whether it needed to be completely rewritten or withdrawn. My experience as a practitioner in the field was also important in assessing the relevance to current practice of some areas of text**G1 Critical analysis).**

To remain at the forefront of practice, the book also had to acknowledge and discuss the changing environment of volunteering and volunteer management in palliative care and to address challenges and issues of concern for practitioners. It was also important to be able to identify new and innovative practice and to bring this into the text. This required on my part a breadth and depth of understanding of the field of volunteering and volunteer management in palliative care **(KU 3 generated through personal research)**.

It was also vital that this text would serve to develop the skills of readers whether new or experienced volunteer managers.

The Editing Challenge

One of the challenges of editing a multi author text of contributions from international authors for an international readership is the range of writing styles, the individual approaches to the subject matter, the lack of continuity between chapters, the terminology used in different countries and ensuring that all chapters are accessible to different audiences in different countries **(G4 complex and new issues/informed judgments)**. These considerations also have to include compliance with the style and requirements of the publisher. It was important also to recognise that for certain authors and the readership that English would not always be the first language and it was important that all text was accessible and jargon free **(C 1 communicate to a range of audiences)**. UK terminology and processes would not necessarily be universally understood and it was necessary to ensure that this was highlighted and clarified in chapters as required. In order to edit effectively I also had to be able to bring together a range of ideas and to be able to

synthesize complex concepts in order to edit texts appropriately without changing meaning or messages **(G1 Critical analysis)**.

I do not believe therefore that it is possible to edit a text aimed at the development of practice in volunteer management in palliative care without some knowledge of either volunteering or of palliative care **(KU1 Critical overview)**. The strength of co-editing meant that I could draw upon my co-editor's knowledge of the wider field of volunteering, volunteer management and experience of editing whilst bringing my own knowledge of volunteering and volunteer management in palliative care and writing for publication **(P5 development and application of new knowledge)**.

One of the opportunities to us as editors of the second edition was to re-order the chapters to improve the links between chapters and flow of the book, starting with perspectives on volunteer management, moving into a 'how to' section on a range of topics from training to support with a final section of case studies from different environments including children's hospices, different countries including USA, Canada, South Africa and India. The flow was further improved by editing chapters and ensuring that where there was a link between the subject matters within chapters that this was picked up and both noted and referenced in the related chapters.

This required the skill to deal with complex issues, understanding the different perspectives from different countries and to ensure through careful editing linking from one chapter to another, ensuring references made in one chapter, for example, to training of volunteers, were picked up and referenced subsequent chapters **(A 5 complex professional issues)**.

It was my responsibility as an editor to check that the information given by authors in chapters was accurate and still relevant, that references were accurate, that the figures and diagrams were correctly referenced following the re-ordering of chapters and that all terms used in the book were clear to all nationalities through a glossary of terms. This required me to make judgements based on my own knowledge and experience in the field of palliative care volunteering **(A1 high level of autonomy/initiative, A2 responsibility for own work and others)**.It was important to remember at all times that the book was

published by an academic publisher, Oxford University Press and that the book would be recommended for inclusion in a number of courses e.g. nursing, medicine and voluntary sector studies **(C2 communicate at standard of published academic work)**.

As an editor I had to learn to employ the standards and methods set out by the publisher, including reading and editing on paper and on screen. I started out to edit on printed text but soon realised that this would double my workload as I had to submit edited text electronically. I therefore had to learn to proof read and edit on screen. As I had never previously edited documents on screen using PDF editing tools, this was a learning experience for me. In my role as editor I had to be able to speed read, proof read for sense, for mistakes and typographical errors and manage the total word count of the book, including the index and glossary **(C3 use a range of software, A4 work in ways which are self-critical)**.

The final stages involved proof reading the full text of the book on two separate occasions, responding to editorial questions, working to very short deadlines and developing the marketing text and target markets.

Reflections on the Process

The project required good administrative and time management skills. It was important to develop a time line, to work to tight deadlines and to agree with my co-editor the most effective way of working together as he was based in London whilst my base was in Dunblane in Scotland. We each undertook 50% of the work and, by agreement, split the chapters evenly between us, allocating them to each of us on the basis of our knowledge and expertise in certain areas. I took the lead role in the administration of the process of editing the book, ensuring that deadlines were met and co-ordinating with the publishers regarding progress. **(A1 high level of autonomy and initiative, A3 demonstrate leadership** Appendices 4:5 and 4:6**)**.

The challenges included commissioning new authors and chapters, managing authors and ensuring that new chapters were submitted on time and letting authors know that their chapters were being withdrawn from the second edition. There was significant responsibility for meeting deadlines and keeping jointly to timescales and ensuring that the book reflected up to date and accurate information **(A5 complex professional issues)**.

At the end of the process my co-editor and I had a short reflective de-brief about the process and identified what had gone well and what could have been better. We reflected that we had worked well together and had brought different perspectives to the editing role, my colleague from knowledge of the wider context of volunteering and mine from the palliative care perspective. We believed that this strengthened the editing process. We both learned a great deal from the complementary knowledge and expertise of the other. My co-editor has significant experience of the policy and practice of volunteering in the wider context and I certainly learned more about this from our discussions and from editing the chapters which Steven wrote for the book. I also drew on his background as an experienced researcher and editor as we debated our approach, that of other publishers and got to grips with OUP's requirements for proofreading, referencing and marketing (Appendix 4:7). I was able to share with Steven my professional knowledge of palliative care and experience as a volunteer manager in both adult and children's palliative care. In doing so I was sometimes challenged by his questioning and deepened my own knowledge and understanding as I reasoned and explained the palliative care perspective.

In terms of improvement, we reflected that we should have managed our time more effectively and set out a more realistic timetable. On reflection we felt that we could have undertaken more research into the international perspective and brought additional information to the book in terms of further development of the innovative practice from other countries through the inclusion of further chapters **(A4 work in ways which are self critical)**.

I have considered as an outcome from the review that there is an opportunity for a second book looking at innovation in volunteering in hospice and palliative care and have

discussed this with my co-editor and Oxford University Press who are excited by the suggestion and keen that this is taken forward.

This was a tremendous learning opportunity to develop existing skills in action research, literature review, critical analysis, managing complex information and in writing for a range of audiences. It was also an opportunity, second to none, in developing new skills in editing, working with a highly respected publisher and understanding the processed involved in developing, editing and publishing a book **(A4 reflective and self-critical)**. I have found my new editing skills invaluable in my work context and apply these when reviewing the structure, content and flow of documents.

The culmination of the work came when the book was published in September 2009 and a book launch was held at the Help the Hospices International Conference in Harrogate in November 2009 (Appendix 4:8). Sales have got off to a good start with 189 copies having been sold by mid- February (Appendix 4:9).

References

1. Scottish Curriculum and Qualifications Framework (2003) Level 12 doctoral level criteria, Retrieved on 10 October 2009 from www.scqf.org.uk.

2 Patton, M (1987). *How to use Qualitative Methods in Evaluation*. London: Sage.

3. Sarantakos, S. (2005). *Social Research*. Basignstoke: The Macmillan Press Ltd.

APEL CLAIM PART 4 **Appendix 4.1**

Copy of book: Volunteers in Hospice and Palliative Care.

Published copy provided separately.

Reference

Scott, R. Howlett S., & Doyle, D. (Eds.) (2009). *Volunteers in Hospice and Palliative Care - A resource for voluntary services managers. (2nd Ed).* Oxford: Oxford University Press.

30 OCT 2007

ISBN:

EDITOR'S AGREEMENT

AGREEMENT DATED 18 SEPTEMBER 2007 BETWEEN:

(1) **OXFORD UNIVERSITY PRESS** of Great Clarendon Street Oxford OX2 6DP ("the Publisher"); and

(2) **MS ROSALIND SCOTT,** Director of Organisational Development, Children's Hospice Association Scotland, Canal Court, 42 Craiglockhart Avenue, Edinburgh, EH14 1LT and **MR** for

Wharf, K[illegible] ("the
K[illegible], Edinburgh, EH12 6JR ("the [illegible]")

WHEREAS

A. The Editor wishes to edit and co-ordinate a script for publication which is provisionally entitled ***Volunteers in hospice and palliative care– a handbook for volunteer service managers, second edition*** ("the Work").

B. The Editor has agreed to edit, co-ordinate and deliver the Work to the Publisher and the Publisher has agreed to publish the Work on the terms of this Agreement.

NOW IT IS HEREBY AGREED AS FOLLOWS:

The Publisher and the Editor hereby accept and agree to the terms of this Agreement, which incorporates the following Schedules which are attached:

SCHEDULE I:	Editor's obligations and specific terms and conditions
SCHEDULE II:	Payments by the Publisher
SCHEDULE III:	Standard terms and conditions

SIGNED by.....

for and on behalf of **OXFORD UNIVERSITY PRESS**

SIGNED by.....
MS ROSALIND SCOTT (EDITOR)

SIGNED by.....
(EDITOR)

SIGNED by.....
ADVISORY EDITOR)

Appendix 4:3

Volunteers in Hospice and Palliative Care: A handbook for volunteer service managers

Proposal for New Edition

Volunteers in Hospice and Palliative Care has had exceptionally strong sales with over 1,100 copies sold since it was published in 2002. The book has received positive reviews and is a valuable resource for both new and experienced Volunteer Services Managers in Palliative Care. It is also of value to a wide range of hospice professionals, many of whom are involved with volunteers in a variety of ways.

As far as we are aware, this is the only text of its kind which is specific to volunteer management in palliative care. In an area where volunteers are such a vital and integral part of the service, where they significantly out number paid staff, this book is a key part of any palliative care professionals' library. As there continues to be a high turnover of staff in this area the book continues to be an extremely helpful guide.

The fields of volunteer management and palliative care have undergone rapid change in recent years and the original edition of the book had now become very dated and would benefit from an update if it is to retain its importance as a key resource for hospice professionals.

It is felt that the book could be strengthened by dividing it into sections, either notional or actual. The suggestions are as follows : Section 1 Introductory section – setting the scene of the landscape of volunteering and volunteering in palliative care – Section 2 – the management guidance chapters and Section 3 Volunteer Management in Action – Case studies of actual programmes. It is suggested that Chapter 3 form the previous edition be removed and a number of additional chapters are proposed.

Proposed Contents List

Chapter 1: Introduction

It is proposed that this chapter remains with slight revision to set the scene and context of volunteering in palliative care.

Chapter 2: The Landscape of Volunteering: Steven Howlett (New Chapter)

Volunteering in palliative care does not exist in a vacuum and is affected by trends and changes in the world of volunteering. This chapter will cover the key issues in volunteering today and set volunteering in palliative care within this context.

Chapter 3: The Managerial Role of the Volunteer Service Manager – Dorothy Bates
New Title: The Management Role of the Voluntary Services Manager

It is proposed that a change to the title of this chapter to "The Management Role of the Voluntary Services Manager would help to update terminology. An amalgamation of this Chapter and Chapter 3 The Position of the Voluntary Services Manager Within the Organisation would reduce overlap and strengthen the chapter. This chapter will covers strategic planning, budgeting, motivation and retention, staff volunteer relationships, and administration. It is also planned that this chapter should include monitoring and evaluation, management competencies, a brief mention of the position of the VSM in the organisation and the importance of volunteering being included in strategic plans.

Previous Edition Chapter 3: The Position of the Volunteer Services Manager within the Organisation.

It is recommended that this chapter is to be deleted and relevant content to be included in chapter 3 in The Management Role of the Voluntary Services Manager.

Chapter 4: Quality Standards: Steven Howlett

Palliative care is set within a number of regulatory frameworks. It is important that a voluntary services manager has key standards within which to assess and review the progress of the service. This chapter will cover a num,ber of recognised quality standards and their use in palliative care: the impact assessment toolkit; Investing in Volunteers and Volunteer Involvement Value Audit. It will also touch on Care Standards for Independent Hospices.

Chapter 5 Selection of Volunteers: Sally- Ann Spencer Gray

This chapter will cover all aspects of the recruitment and selection of volunteers. It will cover all aspects of recruitment, interviewing, the selection process, induction, rejecting candidates and trustee recruitment. A review if this chapter will include some terminology changes and updating to bring it into line with current thinking and best practice on the selection of volunteers.

Chapter 6 Training and Education: Sally-Ann Spencer Gray

This chapter will cover the key aspects of best practice in the education and training of volunteers. It will consider the importance of and elements of training, planning, resources and delivery. This chapter needs only slight review for updating of terminology and a review of the section on Trustee training is required in the light of new charity regulations.

Chapter 7 Support : Gill Hamilton

This chapter will cover the importance of and will outline effective support systems for volunteers in palliative care. The chapter needs some revision in terms of terminology and minor editing to remove small overlaps with previous chapters.

Chapter 8: Legal Issues – Gill Hamilton
New author proposed: Mark Restall

Because of changes in legislation, it is intended that this chapter should be removed completely and be rewritten to cover the following areas: volunteers and employment rights, volunteers and benefits, health and safety, data protection, volunteer drivers, young volunteers and volunteers from overseas.

Chapter 9: Professionals Working as Volunteers: Silke Lean, Patricia McDermott

This chapter covers the definition of a professional volunteer and the issues in management for the voluntary services manager. It also covers specific recruitment issues, relationships with staff, supervision, accountability and policy. The chapter needs revision only of terminology.

Chapter 10: Ethical Issues for VSMs – Nicola Grant
New authors proposed: Steve McCurley & Ros Scott

It is intended that this chapter be withdrawn and rewritten by joint authors covering the broad aspects of ethics and volunteering and the specific areas involved in palliative care for example volunteer and paid nurses in the same team.

Chapter 11: Volunteers as Bereavement Counsellors: Jenny Osterfield

This chapter covers all aspects of volunteers as bereavement counsellors and includes the relationship between volunteers and the community, the selection, training, supervision and support of volunteers, volunteers working with clients,

compassion fatigue, health and safety, the hospice approach to bereavement and bereaved children. It is proposed to leave this chapter unchanged.

Chapter 12: Volunteers in Children's Hospices – Ros Scott

This chapter will highlight the specific needs of voluntary services in children's hospices. This area of volunteering has moved on considerably since the book was first put together and consequently the chapter needs to be completely revised. It will highlight the differences between children's hospices and adult hospices and specific practice issues relating to the management of volunteers in this setting.

Chapter 13: Volunteers in Comprehensive Palliative Care Service: Rosemary Hanley, Australia

This chapter covers the definition of a comprehensive palliative care service, conditions governing the working of volunteers, volunteer roles, initial and ongoing training, the role of the VSM and 'burn out'. No change to this chapter is required.

Chapter 14: Volunteers Working in a Comprehensive Palliative Care Service: Kathleen Defellippi, South Africa

This chapter covers the hospice setting, the impact of HIV/AIDS, history of volunteer involvement, selection, volunteer staff relations, roles of volunteers, training, support, value of volunteers to the service. No change to this chapter is required.

Chapter 15: Volunteers Working in a Tertiary Referral Teaching Hospital: Suzanne O'Brien and Ellen Wallace, Canada

This chapter covers the principles of volunteer involvement, the context of the volunteer programme, team working, volunteer profiles, the volunteer experience, training and ongoing education. It also includes discussion on the challenges and opportunities for the Voluntary Services Manager. No change to this chapter is required.

Chapter 16: The Palliative Care Programme in Kerela, India – Dr Suresh Kumar

This chapter will outline an innovative programme of volunteering in palliative care. People based in the local community are trained as volunteers and identify people

who need additional care and support and refer on to professionals. It will cover recruitment, training and the structure of the system.

Ros Scott
Steven Howlett

Appendix 4: 4
Submission of Book

Volunteers in Hospice and Palliative Care

Sunday, 1 March, 2009 10:00 PM

From:

"Ros Scott" <rosc.scott@btinternet.com>
Add sender to Contacts

To:

nicola.ulyatt@oup.com

Cc:

"Steven Howlett" <S.Howlett@roehampton.ac.uk>, derekdoyle@waitrose.com, rosscott@chas.org.uk

Message contains attachments

1 File (984KB)

-  Final Edited Chapters 0309.zip

Dear Nicola,

Please find attached the final edited copy from Steven and myself of Volunteers in Hospice and Palliative Care. It is complete apart from Chapter 4 Quality Standards which I know Steven has spoken to you about.

I have still to hear back from a couple of comtributors about their titles and I have had no more word from Derek Doyle although I will send him a copy of this email.

Please don't hesitate to get back in touch if you have any questions.

Appendix 4:5

Re: Quality Chapter

Tuesday, 17 March, 2009 8:03 PM

From:

"Ros Scott" <rosc.scott@btinternet.com>
Add sender to Contacts

To:

rosscott@chas.org.uk

Cc:

Message contains attachments

1 File (108KB)

- Chapter 4 Considering Quality and Measuring Impact.doc

Hi Steven,

I really like the Chapter, how you write and have pulled together a wide and complex area. I have made a few suggestions and comments - please feel free to ignore. I haven't spell checked or formatted as you had said you wanted to tidy it up a bit.

Hey .. we did it!!

Bye for now

Ros

--- On **Tue, 17/3/09, S.H** wrote:
From: S.H
Subject:
To: rosscott@chas.co.uk
Cc: rosc.scott@btinternet.com
Date: Tuesday, 17 March, 2009, 12:29 AM

```
Dear Ros,

At last - quality and impact! I need to speak to Nic and make sure it
is still OK to send. This is still rough as you can see, but I think I
can tidy quite quickly (depending on what you say) - it is a bit long,
but what do you think?

Steven

Consider the environment. Please don't print this e-mail unless you
```

Appendix 4: 6 Marketing Information

Medical Books Department
Great Clarendon Street, Oxford, OX2 6DP,
United Kingdom

OXFORD
UNIVERSITY PRESS

Author Questionnaire

Book Title: *Volunteers in hospice and palliative care– a handbook for volunteer service managers, second edition*

OUP Commissioning Editor: Nicola Ulyatt

Thank you for taking the time to fill in this form, which is extremely important to us. We will use your answers as we produce and promote your book, and they will form the basis of our marketing plans and publicity material. We start planning the marketing of our books very early in the production process or, in some cases, before manuscript delivery, so it is vital that we have your advice and suggestions as early as possible. Marketing from the Oxford office is directed to the UK, Europe, the Middle East and parts of South America and the Far East. However, suggestions for other parts of the world will be passed on to the appropriate OUP branch.

Explanatory notes have been included within the form where possible. If you have any further questions, please contact your Commissioning Editor, to whom you should also return the completed form when, or before, you deliver your typescript.

If you have co-authors or co-editors, please note that each of you will receive a separate copy of this form.

This version of the form is intended to be completed on screen using Word. Please add more lines to each section as required. If you require a hard copy version to be filled in by hand/on a typewriter, please let us know.

Part 1: Your contact details and biographical information

Please complete your preferred contact details below:	
Name and Title	Mrs Ros Scott
Address	Children's Hospice Association Scotland, Canal Court, 42 Craiglockhart Avenue, Edinburgh
	EH14 1LT
Tel	0131 444 14005
Fax	
Email	rosscott@chas.org.uk

*Your name **exactly** as it should appear on the front of book, title page, and any publicity material:*
Ros Scott

Your present position and affiliation exactly as they should appear on the title page, and any publicity material:
Director of Organisational Development, Children's Hospice Association Scotland

Your nationality and place and date of birth (for British Library and Library of Congress purposes):

Appendix 4:7

Wednesday 25 November 2009

Book launch – Volunteers in hospice and palliative care: a resource for voluntary service managers
12.15 in Main auditorium

The launch of the second edition of this popular title from Oxford University Press follows the conference session 'Volunteering: does our future depend on it?' at which Ros Scott and Steven Howlett, co-editors of the book, will speak.

Poster discussion session
12.20 in Hall Q theatre

Authors of the highest scoring abstracts of poster presentations, submitted via the Call for Papers, have been invited to give short oral presentations about their posters.

AGM of the Forum of Chairmen of Independent Hospices
12.30 - 13.15 in Queen's Suite 3

A meeting for members and prospective members of the Forum, who may include both hospice chairmen and trustees, at which a new Chair will be elected.

Investing in hospice leadership and management
12.30 - 13.15 in Conference suite 2

Help the Hospices is working with Cass Business School's Centre for Charity Effectiveness to scope the development needs of hospice leaders and managers in preparation for constructing an accredited and hospice specific development programme. This will be a short but action-packed meeting, aimed at stimulating thinking and generating ideas.

Open meeting for hospice researchers
13.00 in Hall Q theatre

An open meeting, chaired by Professor Sheila Payne, to encourage researchers in hospices to develop a supportive network.

Film screening
16.15 - 17.00 in Hall Q theatre

Screening of two films: a ten-minute discussion piece on how South African hospices are adapting to the pandemic of HIV; and 'Survivors guide – the two faces of opium', a 25-minute film investigating opium's use and abuse in Kyrgyzstan.

Help the Hospices AGM
17.00 in Main auditorium

The AGM is open to all but any voting will be restricted to the representatives of member hospices.

The meeting will include the formal business of the organisation but also an update of our activity over the last year and in particular feedback from the regional road show meetings held in the Autumn. This will also be an opportunity for members to put questions to the chief executive and the Board and formal notice will be sent to all member hospice representatives.

Conference dinner
19.15 Pre-dinner drinks in Mezzanine
20.00 Dinner in Hall D

For those who booked in advance, the conference dinner will be held at Harrogate International Conference Centre. Pre-dinner drinks can be bought from the bar on the Mezzanine from 7.15pm onwards and dinner will be served promptly at 8pm in Hall D.

Please bring your dinner ticket with you.

We regret that we cannot take any more bookings for the dinner unless any tickets have been returned. Please ask at our registration desk about the availability of returned tickets.

Dr Phil Hammond, a medical doctor who has become noted as a comedian and commentator on health issues, will be giving an after dinner speech.

Flag this message

Appendix 4: 8 Sales Figures

Sales update

Monday, 15 February, 2010 11:00 AM

From:

"WRIGHT, Jenny R." <jenny.wright@oup.com>

Add sender to Contacts

To:

rosc.scott@btinternet.com

Hi Ros

Thanks for your call just now. I'm pleased to let you know that your book has sold 189 copies so far, which is really good progress in just under 5 months worth of sales.

Let me know if you need any more information.

Best wishes

Jenny

Assistant Commissioning Editor, Medicine

Oxford University Press

Great Clarendon Street

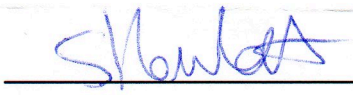
Oxford OX2 6DP

APEL CLAIM Part 4

Rosalind Scott
Matriculation No: 030015787

As a co-editor, I jointly developed a proposal for the book with my co-editor, shared the editing role for the chapters, jointly liaised with authors and with the Oxford University Press. I also contributed one chapter as a sole author and one chapter as a co-author.

The percentage of work undertaken by me in this project was 50%.

Signed: 

Steven Howlett, Co-Editor: Volunteers in Hospice and Palliative Care.

APEL CLAIM Part 5 **Rosalind Scott**

Matriculation No: 030015787

Contents

1. Claim document

2. Appendix 5:1 Copy of chapter: “Volunteers in a Children’s Hospice”
   In published copy of book: Volunteers In Hospice and Palliative Care provided separately.

APEL CLAIM Part 5 **Rosalind Scott**

Matriculation No: 030015787

Title: Volunteers in a Children's Hospice

Introduction

The purpose of this APEL claim is to demonstrate that the writing, research and publication evidenced in this paper was undertaken at doctoral level. This paper reports the work undertaken in revising and rewriting one chapter, Chapter 12: "Volunteers in a Children's Hospice" contributed to the second edition of the book "Volunteers in Hospice and Palliative Care" published in September 2009 by Oxford University Press. Whilst I co-authored a second chapter, I am making a claim based only on Chapter 12 which is attached as Appendix 5:1.

Structure of Claim Document

This paper provides evidence under the five headings of the Scottish Curriculum and Qualifications Framework Level 12 doctoral level criteria (SCQF, 2003) (Appendix 1:2)

- Knowledge and Understanding
- Practice: Applied knowledge and understanding
- Generic Cognitive Skills
- Communication, ICT and numeracy skills
- Autonomy, accountability and working with others

Under each of the headings I will evidence the work undertaken for the project against the characteristic generic learning outcomes. As these are intended to give a general overview of learning outcomes, I will endeavour to match these as closely as possible, recognising however that not all evidence will match exactly.

Background to Project

I was approached by the editor of the first edition of Volunteers in Hospice and Palliative Care and asked to write a definitive and stand alone chapter on volunteering in children's hospices for the book.

This first edition was published in 2002 and was, as far as I am aware, the first text which concentrated on volunteering in hospice and palliative care settings. The book focussed mainly on volunteering in adult palliative care settings and comprised 14 chapters, including a foreword by Dame Cicely Saunders who was a highly respected professional in the field. She is known throughout the world as the founder of the modern hospice movement.

The chapters were commissioned as 'stand alone' pieces of work and most were written by practising voluntary services managers, as was I at that time. I was also advised by the editor at that time that the chapter was intended to be of practical help to Voluntary Services Managers, to base it on practice rather than research and to keep the number of references to a minimum. Mine was to be the only chapter on volunteering and children's hospices. As such it also required to give an insight beyond volunteering and into the work of children's hospices.

When approached to become co-editor of the second edition of the book, as part of the review of the first edition, my own chapter was scrutinised. It was clear that it was now very out of date and rather than merely editing to bring up to date, I decided to undertake a complete rewrite.

Critical Analysis

Before making this decision, I undertook a critical analysis of the chapter. The criteria for analysis included:

- the relevance to current practice

- accuracy of information in the light of changing practice
- how well the chapter fitted with other chapters
- gaps in the topics covered
- quality of writing
- readability and flow of the chapter and also in relation to the book as a whole

As the book was aimed at an international audience with authors from UK, Australia, Canada, South Africa and India, before rewriting my chapter I needed to have a critical and in depth overview and understanding of volunteering in children's palliative care at least in the UK, and some understanding of other countries **(KU 1 Critical overview; KU2 Leading knowledge)**. It was important also to analyse the principles and theories contained in my first chapter in order to assess whether these met with current practitioner thinking and best practice. I was therefore able to clearly identify which parts of the chapter were out of date and which concepts could be kept. It was also important to consider new theories, practices and approaches, drawing upon current literature but also experience as practitioners in the field of volunteer management in children's hospices and consider how these might be introduced. Having been a volunteer manager in palliative care since 1991 and in a children's hospice organisation since 1996, I drew heavily on my own experience and knowledge as a practitioner and that of my peers in the UK **(KU 2 Leading knowledge)**.

In reviewing the chapter, it was evident that current volunteering practice in children's hospices had undoubtedly developed since 2001 when it had been first written. Volunteers, for example, were now more widely used in an increasing range of roles, and more children's hospices involved volunteers as part of the team. Considering the chapter within the context of a new edition, it was clear that there was duplication and overlap with other chapters, for example in relation to recruitment and selection and legal issues. One key aim of my co-editor and I was to reduce overlap, repetition and improve flow and sense between chapters. There was therefore an opportunity for me to ensure that any duplication of information was removed and that links and references were made to related information

contained in other chapters **(A1 High level of autonomy; A2 Full responsibility for own work; A4 Work in ways which are self critical).**

On evaluating my work critically, I felt that the quality of writing could also be significantly improved. The original chapter had been my first experience of writing such a large piece of work and my skills had developed over the years **(A4 Work in ways which are self critical)**.

Preparation for the Chapter

Before starting to write, it was important to refresh my knowledge in volunteering in children's palliative care to ensure that my thinking and understanding was as in depth and up to date as possible. I did this by reviewing the literature, of which there is a dearth, drawing on the experience of colleagues in the field, from conferences and from discussions and notes of meetings from the children's hospice Volunteer Managers Forum. As previously mentioned I also drew heavily on my own experience as a practitioner in the field and on my own research into volunteering in children's hospices **(P1 Range of skills and techniques; P3 range of techniques of enquiry; P4 Investigative projects to deal with new issues).**

Whilst there was a dearth of literature in the area of volunteering in children's hospices, there was much knowledge and practice which could be taken and applied from the adult sector, for example understanding volunteer motivations; the provision and structure of induction and training **(P6 Practice in the context of new problems and circumstances)**.

As the chapter was considered to be a definitive text in the field, there was significant responsibility to bring information, not only at the forefront of practice, but also to introduce new perspectives and creative ideas to catch the imagination of readers and to challenge thinking and inspire developments in their services **(G3 Creative and original responses; P 5 New knowledge, understanding and practice)**.

Developing Practice

Whilst there is significant range of information relating to volunteer management, there is little written about volunteering in children's palliative care. I was aware that my chapter would be included in a book with an international audience, which was also a recommended text for a number of courses. The first edition had been very much viewed as an authoritative text book for senior managers, clinical staff, volunteer managers and volunteers in palliative care **(C1 Communicate with a range of audiences; C3 Published academic work)**. The chapter content therefore had to be at the forefront of practice in children's hospices, volunteering and volunteer management in this setting. I, as an author, had to build and develop my own knowledge to this level to ensure that the chapter reflected this **(P2 Forefront of specialisms)**. As previously discussed on pages 2 and 3, I approached this through a variety of ways.

In order to be able to re-write the chapter effectively, I needed to bring together my research skills gained through previous studies, literature review skills; my own research findings and my experience as a practitioner in volunteer management **(P1 Range of principal skills techniques and practices; P2 Range of standard techniques; P3 Standard and specialised research techniques).** The application of research skills provided a framework and methodology which I used not only for reviewing the book, but also for the purpose of rewriting the chapter. I applied the same methodology as I used for the book. As mentioned in APEL Claim Part 4, I approached the task using a qualitative case study method. Using Patton's (1987) definition the 'unit of analysis' in this situation was my chapter first written in 2001.

To remain at the forefront of practice, the chapter also had to acknowledge and discuss the changing environment of volunteering and volunteer management in children's hospices and to address challenges and issues of concern for practitioners, for example matching expectations with applications; unsuitable applicants; recently bereaved parents. Other challenging areas included safe, effective recruitment and selection to work with children,

appropriate roles to be undertaken by volunteers; bereavement and support and burnout **(A5 Complex ethical issues; P5 New knowledge, understanding and practices)**. It was also important to be able to identify new and innovative practice and to bring this into the text for example, the range and diversity of roles, strategy for supporting volunteers and the debate surrounding the involvement of young people as volunteers. This required a breadth and depth of understanding of the field of volunteering and volunteer management in children's palliative care **(KU 3 Generated through personal research)**.

It was also vital that this text would serve to develop the skills of readers, whether new or experienced volunteer managers. This was especially important in developing knowledge and understanding of the specific issues for volunteering and volunteer management in children's hospices from readers out with this field.

My role as an author

As a contributing author, I had to ensure that during the preparation undertaken for this chapter; new concepts were identified; my own professional experience in the field of volunteer management in children's and adult's palliative care was up to date; and that the chapters would bring new and innovative ideas which would add to the body of knowledge in the field **(G2 Conceptualise and offer original and creative insights; C 1 Significant range of advanced and specialised skills)**. I had to sift and bring together a diversity of practice in children's hospices into one chapter; develop new insights and questions to challenge current thinking for example recruitment and selection; volunteer roles; induction; support and young volunteers **(A5 High level of autonomy; P2 Practices and materials at the forefront of one or more specialisms; G3 Creative and original responses; C2 Communicate at appropriate level/range of audiences; C3 Standard of published academic work)**. In children's hospices, there is some resistance to the involvement of volunteers with children and families. This results in volunteers being involved in peripheral roles such as fundraising and retail. My aim in writing the chapter was to introduce examples of a range of ways in which volunteers can bring experience and

skills to a diverse range of areas, including involvement with children and families **(G4 Complex and new issues/informed judgments)**.

As an author, I had to comply with the style and requirements of the publisher. It was important also to recognise that my chapter could have an international audience and that English would not always be the first language. My writing needed to be clear, accessible and free from jargon. **(C1 Communicate to a range of audiences)**.

As editor and author, it was important that my chapter was independently reviewed and edited. I therefore submitted my chapter to my Co-editor. As he had no knowledge of practice in the field of volunteering in children's palliative care, I felt that this would bring rigour in ensuring that my writing was accessible and clear. He made very few changes to the chapter and commented that it was of a very high standard.

It was important to consider at all times that my chapter was part of a book published by an academic publisher, Oxford University Press and that the book would be recommended for inclusion in a number of courses e.g. nursing, medicine and voluntary sector studies **(C2 Communicate at standard of published academic work)**. This chapter was also intended to share best practice and help hospice staff new to the field, develop their own knowledge and skills **(C2 Communicate at an appropriate level)**.

Reflections on the Process

Being both an author and editor required a high level of administrative and time management skills. My chapter had to be reviewed and submitted on time within a wider timescale required for the submission of the full book. Had my chapter been delayed in submission to my co-editor, this would have had a subsequent effect on the project. As my co-editor and I anticipated the need to be flexible with timescales for other authors, I felt a significant responsibility to complete my work within agreed dates. I therefore had to take full responsibility for developing a project timescale for my chapter and ensuring through

effective time management that it was submitted on time **(A1 High level of autonomy and initiative; A2 Full responsibility for own work; A3 Demonstrate leadership)**.

It was an interesting experience undertaking a critical analysis of my own work some six years on. On reflection I was both proud of my initial work, but could see significant opportunity for development. It was clear that I had not paid sufficient attention to the content of other chapters in the first edition and this had led to considerable overlap and repetition. In rewriting the chapter, I spent a considerable amount of time cross referencing the content between my chapter and others and deleting information which was contained elsewhere. I had also not made it clear that the chapter intended to highlight specific practice which was different in children's hospices. This I was able to do during the revision.

I remember feeling completely overwhelmed when I started to write the chapter for the first edition, struggling with structure content and where to begin. I found the direction to develop and 'authoritative' piece of work very daunting at that time. This time I was much more confident in approaching the task seven years later and found that my work for my MSc in undertaking a range of practitioner research projects had developed my confidence in my abilities as both a practitioner and researcher. I was able to draw upon some of my own research and also my skills in critically reviewing and analysing literature. I was also much more confident in the writing task. It was rewarding to see evidence of the development of my skills during this period of time and to realise that I could bring more to the chapter this time **(A4 Work in ways which are self-critical)**.

On reflection, however, there are however still areas of weakness in the chapter. This could be strengthened by a more detailed discussion of the roles which volunteers undertake and the benefits which they bring to children and families. More could have been written about the way in which young volunteers could be involved. Perhaps a critically analysis of adult hospice volunteering models and their suitability to children's hospices might have been particularly helpful in a book which was focussed almost entirely on adult services **(A4 Reflective and self-critical)**.

This was, however, a tremendous learning opportunity to develop my knowledge of children's palliative care and volunteering within this field. I also was able to further develop my skills in research, literature review, critical analysis and in writing for a range of audiences. It was also a tremendous opportunity to develop my skills as an author through working with my co-editor and a highly respected publisher **(A4 Reflective and self-critical)**.

The culmination of the work came when I saw my chapter in print when the book was published in September 2009.

References

1. Scottish Curriculum and Qualifications Framework (2003) Level 12 doctoral level criteria. Retrieved on 10 October 2009 from www.scqf.org.uk.

2. Patton, M (1987). How to use Qualitative Methods in Evaluation, London: Sage.

3. Scott, R (2009). Volunteers in Hospice and Palliative Care. A Resource for Voluntary Services Managers, Oxford: Oxford University Press.